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IHS National Diabetes Program

Special Diabetes Program for Indians

Interim Report to Congress

January 2000

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Report to Congress

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Table of Contents

| | |
|---|----|
| Executive Summary | v |
| Background | 1 |
| <i>Balanced Budget Act Legislation</i> | 1 |
| <i>IHS National Diabetes Program</i> | 2 |
| History and Mission Statement | 2 |
| Diabetes Prevention Activities | 2 |
| Program Evaluation | 5 |
| Model Diabetes Programs | 5 |
| Collaborations and Partnerships | 7 |
| <i>Scope and Impact: Diabetes Epidemiology</i> | 9 |
| Prevalence of Diabetes | 9 |
| Etiology of Diabetes in AI/ANs | 12 |
| Diabetes Mortality | 13 |
| Diabetes Complications | 13 |
| Demographics of AI/AN Communities | 14 |
| <i>History of Grants</i> | 16 |
| Tribal Consultation | 16 |
| Diabetes Workgroup | 16 |
| Implementation Guidelines for Grant Program: Director's Final Decisions | 18 |
| Tribal Leaders Diabetes Committee | 20 |
| Area Consultation | 20 |
| Grant Application | 21 |

| | |
|--|----|
| <i>Program Challenges</i> | 22 |
| Grants Program Baseline Information | 24 |
| <i>Overview</i> | 24 |
| <i>Request for Application</i> | 24 |
| <i>Reporting Requirements</i> | 26 |
| <i>Year 1 Grant Application Review</i> | 28 |
| Analysis of Current Program Activities | 34 |
| <i>Introduction</i> | 34 |
| <i>Method</i> | 34 |
| <i>Findings</i> | 35 |
| Program Emphasis on Target Age Groups | 35 |
| Change in Focus on Target Age Groups: Elders and Adults | 35 |
| Change in Focus on Target Age Groups: Children and Adolescents | 36 |
| Emphasis on High Risk Groups | 36 |
| Change in Focus on High Risk Groups (1 of 2) | 37 |
| Change in Focus on High Risk Groups (2 of 2) | 37 |
| Target Groups for Nutrition Information | 38 |
| Increase in Nutrition Activities | 38 |
| Use of Commodity Foods | 39 |
| Target Groups for Delivering Nutrition Information | 39 |
| Program Increase in Physical Activity for Adults | 40 |
| Increase in Physical Activity for Programs for Youth | 40 |
| Diabetes Screening Activities | 41 |
| Screening, Referral, and Treatment for Diabetes Complications | 41 |
| Education for People with Diabetes | 42 |
| Community-based Diabetes Education (1 of 2) | 42 |
| Community-based Diabetes Education (2 of 2) | 43 |
| Education for Health Professionals | 43 |
| Traditional Approaches | 43 |
| Developing or Enhancing a Diabetes Program | 44 |

| | |
|---|----|
| Improved Clinical Management Practices | 44 |
| Change in Program Activities as a Result of the Grant Funds (1 of 2) | 45 |
| Change in Program Activities as a Result of Grant Funds (2 of 2) | 45 |
| Program Barriers | 46 |
| New Providers Added to the System | 46 |
| Unfilled Staffing Needs | 47 |
| Technical Assistance Needed from the IHS Diabetes Program | 47 |
| General Technical Assistance Needed | 48 |
| Technical Assistance in Evaluation | 48 |
| <i>Conclusion, Discussion, and Recommendations</i> | 49 |
| <i>Data Improvement Fund Distribution</i> | 50 |
| <i>Program Surveillance Activities</i> | 51 |
| Preventive Services | 51 |
| Cardiovascular Disease | 54 |
| Amputations | 58 |
| Dialysis | 60 |
| Diabetes and Pregnancy | 63 |
| Future Directions | 67 |
| <i>National Diabetes Prevention Center</i> | 67 |
| <i>Regional Meetings</i> | 68 |
| <i>Diabetes Education Reimbursement</i> | 69 |
| References | 71 |
| Appendices | |
| <i>Grant Distribution Tables: Composite and by IHS Area</i> | |
| <i>Data Improvement Funds by IHS Area</i> | |
| <i>Diabetes Funding Allocation Methodology</i> | |
| <i>IHS Diabetes Care and Outcomes Audit</i> | |
| <i>IHS National Diabetes Program Partnerships</i> | |
| <i>Clear Visions-Grant Program Informational Bulletin and Diabetes Monograph Series</i> | |

Executive Summary

The Balanced Budget Act of 1997 provided \$150 million over 5 years to Indian Health Service (IHS) for the establishment of a *Grants for Special Diabetes Program for Indians* focused on “the prevention and treatment of diabetes.” The IHS was instructed to conduct an evaluation of the grant program and provide an interim (year 2000) and final (year 2002) report to the Congress.

The challenge is great. Significant and positive changes in diabetes activities have occurred in American Indian/Alaska Native (AI/AN) communities as a result of the diabetes grant funds. Here is a list of accomplishments:

Tribal Consultation

Grant program development involved the full participation of tribes and tribal leaders, urban Indian organizations, and IHS staff. The IHS Director established the Tribal Leaders Diabetes Committee to create a partnership between tribes and IHS for ongoing input and guidance on diabetes issues.

Grant Awards

Grants were awarded to 318 programs under 286 administrative organizations within the 12 IHS Areas. There were 27 grants awarded to IHS programs, 33 grants awarded to urban programs, and 258 distributed to tribal programs.

Diabetes Prevention

- ! Sixty-seven percent of the grant programs are focused on primary and secondary diabetes prevention. Thirty-two percent are focused on tertiary diabetes prevention.
- ! More diabetes prevention efforts now focus on elders (75%); young adults (68%); adolescents (55%); school age children (42%); and preschool age children (33%).
- ! Three-fourths of programs now focus more on clients with newly diagnosed diabetes; 68% of grant programs focus more on family members of people with diabetes; and 37% focus more on pregnant women as a result of the grant funds.
- ! More emphasis is now placed on addressing preventive measures in adults who are overweight (71.5%), people with high blood pressure (70%), children who are overweight (56%), and on tobacco users (42.6%).

Enhancement of Diabetes Care and Education

As a result of these grant funds, programs have both enhanced existing diabetes activities and developed new ones. These activities are known to improve diabetes care to patients.

- ! A significant number of programs use traditional approaches in their diabetes programs, including story-telling (34%), talking circles (35%), and use of traditional herbs or medicines (28%). Traditional approaches help support and influence positive diabetes self-management behaviors within communities.
- ! AI/AN communities established new diabetes teams (29%) and improved existing diabetes teams (42%).
- ! AI/AN communities created new diabetes registries (42%) and improved existing diabetes registries (48%).
- ! AI/AN communities established new diabetes clinics (21%) and improved existing diabetes clinics (43%).

Community Involvement

The diabetes grant funds have afforded tribes the opportunity to address diabetes prevention where it needs to be addressed--at the tribal community level. Significant advances in the development of diabetes programs have been made. New diabetes care networks have formed within and between tribal communities. They are learning from each other which diabetes prevention strategies work in AI/AN communities. This grant opportunity has allowed tribal communities to move further along their paths to wellness and diabetes prevention. But these funds were “seed money,” just enough to get programs started. Five years is not nearly enough time to accomplish the goal of diabetes prevention.

The advances achieved in AI/AN communities as a result of these funds will be lost without the means to continue and expand the established programs. AI/ AN communities will need continued funding beyond the five years allowed through the Balanced Budget Act of 1997 to continue to implement and expand upon the valuable lessons learned through this process. Diabetes prevention on all levels should bring the health of this population to the same level as that of all Americans in the next millennium. With these grants, American Indian and Alaska Native communities are finding their own paths to diabetes control and better health.

Background

Balanced Budget Act of 1997 - P. L. 105-33

The Balanced Budget Act of 1997, signed by the President on August 5, 1997, made available \$150 million of new funding to the Indian Health Service (IHS) through *Grants for Special Diabetes Program for Indians*. The purpose of this legislation was to provide "services for the prevention and treatment of diabetes." These services were to be provided at Indian health facilities operated by the IHS, Indian tribe or tribal organizations, and urban Indian organizations. The funds were to be distributed as grants over a 5-year period, at a rate of \$30 million a year.

The legislation also stipulated that the Secretary of Health and Human Services would evaluate the diabetes grant programs established by the Act and submit an interim report of the evaluation to Congress by January 1, 2000, and a final report by January 1, 2002.

The congressional legislation came in the wake of increasing public concern about the human and economic costs of diabetes in the United States and its growing prevalence in vulnerable populations, particularly in American Indians and Alaska Natives (AI/AN). This concern, shared by most members of Congress, resulted in bipartisan support for several funding measures in the summer of 1997 addressing the diabetes problem.

Additional funding to expand diabetes-related activities in AI/AN communities came from two separate appropriations acts. The 1998 Appropriations Act for the Department of the Interior included \$3 million for the IHS National Diabetes Program. Because the appropriation language required "grants," the IHS funding was added to the *Grants for Special Diabetes Programs for Indians*. The 1998 Appropriation Act for the Department of Health and Human Services included \$2 million for the Centers for Disease Control and Prevention (CDC) to establish a national diabetes prevention research center. In accordance with Congressional intent in enacting the legislation, the Diabetes Prevention Center was to be established in Gallup, New Mexico.

The Indian Health Service is pleased to submit this interim report to the Congress documenting activities through December 31, 1999, of the *Grants for Special Diabetes Programs for Indians*, the program made possible by this legislation.

IHS National Diabetes Program

History and Mission Statement

Recognizing the severe impact of diabetes on AI/AN communities in the U.S., the National Commission on Diabetes in its 1976 landmark report to Congress called for a "comprehensive clinical management program for diabetes mellitus within the Indian Health Service." The present IHS National Diabetes Program has its origins in this recommendation.

The mission of the IHS National Diabetes Program, based in Albuquerque, New Mexico, is to develop, document, and sustain a public health effort to prevent and control diabetes in American Indian and Alaska Native peoples. The agency promotes collaborative strategies for the prevention of diabetes and its complications in the 12 IHS Service Areas through a network of 19 Model Diabetes Programs and 13 Area Diabetes Consultants (Appendix F). The agency also disseminates current information about all aspects of diabetes surveillance, treatment, education, and prevention.

Diabetes Prevention Activities

Diabetes prevention activities include primary, secondary, and tertiary prevention. **Primary prevention** involves preventing the onset of diabetes in persons at risk for the disease.

Secondary prevention focuses on screening people for diabetes and on screening and treatment programs for people with diabetes in order to control blood sugar levels and other health problems that could contribute to the onset of diabetes complications. **Tertiary prevention** involves screening and treatment programs to reduce disability from the long-term complications of diabetes affecting the blood vessels, nerves, heart, and kidneys.



We are starting to accept this disease and think of it as our fate. We're not talking about how we can stop the disease. What we're saying is, "When am I going to get it?" We just opened a dialysis center, and I'm sad that we had to build it.

Joyce Dugan, former Chief, Eastern Band of Cherokee

Primary Prevention

Epidemiological studies in a wide range of publications have consistently shown a strong association of exercise and weight control with reduced risk for diabetes. Moreover, several primary prevention trials show reduced incidence rates of diabetes in high-risk individuals exposed to nutrition and exercise interventions compared with controls. Given the magnitude of the population at high risk for diabetes in AI/AN communities and the growing evidence supporting diabetes primary prevention, AI/AN community leaders have strongly advocated programmatic support for diabetes primary prevention programs. Accordingly, the IHS diabetes programs have supported many activities that directly and indirectly target diabetes primary prevention. These include:

- ! Community fitness and nutrition programs
- ! Primary school health education curricula
- ! Initiating, distributing, and evaluating selected preventive strategies in the IHS Model Diabetes Programs

In addition, the IHS diabetes programs ensure that IHS populations are included in major prevention studies conducted within the United States. For example, the IHS is a cosponsor with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the *Diabetes Prevention Program* (DPP), a national multicenter research study. The DPP research objective is to determine whether type 2 diabetes can be prevented in those at high risk for the disease. Volunteers from four AI/AN communities (Pima Tribe at Gila River and Salt River, AZ; Navajo Tribe at Shiprock; NM; Zuni Pueblo, NM) who are at high risk for diabetes are participating in the DPP.



Some tribal leaders will say “We’re going to beat this disease. We have to do something.” The diabetes money is a start. It’s only going to scratch the surface. Unfortunately, with the IHS’s limited resources they’ve only been able to focus on treatment--and very minimal treatment it seems. Nothing as innovative as we’d like to see, but the diabetes money has us thinking more about the community-based prevention side . . . The diabetes money is a step in the right direction.

Joyce Dugan, former Chief, Eastern Band of Cherokee

Secondary Prevention

IHS secondary prevention programs operate at several levels. The IHS promotes screening programs for early diagnosis of diabetes and develops strategies to improve blood sugar control, hypertension, blood lipids, and other health problems to reduce diabetes-related complications. These strategies include:

- ! Adaptation and dissemination of medical and educational standards for use in Indian health care facilities
- ! Development of the *IHS Diabetes Care and Outcomes Audit* to assess diabetes care and education
- ! Development of professional education and culturally relevant patient education materials
- ! Collaboration with the International Diabetes Center in Minneapolis, Minnesota, to disseminate practice guidelines based on Staged Diabetes Management™ (SDM), a systematic approach for scientifically-based clinical decision-making in diabetes care. The SDM™ guidelines are adapted locally by clinic and tribal community members for use in local IHS and tribal health care facilities.

Tertiary Prevention

Tertiary prevention activities center on refining, promoting, and measuring the implementation and outcomes of specific services to prevent disability from diabetes-related complications. Some of these services include:

- ! Foot and eye screening
- ! Blood lipids and blood pressure measurements and treatment
- ! Screening for proteinuria and serum creatinine to assess kidney function



Just don't assume that we know. We don't. You need to show us. You have to show me. You can tell me. You can give me brochures to read. I'll read those later and suddenly say "well what is this doing in here or where did I get this?"

The diabetes is a constant struggle because my husband never did believe that he was sick. He says "There is nothing wrong with me," but the toll that diabetes has taken on him . . . he's blind, he has an amputation below the knee and lost a toe on the other leg.

Juanita Atone, Kiowa, husband has diabetes, married 52 years

Program Evaluation

The IHS has been a leader in developing a diabetes care surveillance system, the annual *Diabetes Care and Outcomes Audit* carried out voluntarily in Indian health facilities, to track performance on more than 87 indicators to study trends over time (Appendix D). The *Diabetes Care and Outcomes Audit* monitors use of standards and outcomes of diabetes care, including glycemic and blood pressure control, screening for complications, and preventive health services such as dilated eye exams. The system is based on IHS Standards of Diabetes Care, which have been in place since 1985 and are updated every 2 years. In the 1998 IHS *Diabetes Care and Outcomes Audit*, 11,581 charts were reviewed representing care to 70,751 patients at 190 IHS and tribal health facilities in the 12 IHS Areas.

This diabetes care surveillance system has been instrumental in the improvement of diabetes care practices in many Indian health settings. For example, in a special program in Alaska and in northern Minnesota from 1989-93, lower extremity amputation rates were reduced by 50 percent in people with diabetes who received complete foot screening and protective footwear¹.



IHS has developed a protocol so there's a standard way of categorizing the disease and as a result, treatment becomes more uniform and more able to meet the needs of the individual . . . a common approach to treating the disease.

Ray Granboise, Turtle Mountain Band of Chippewa, Service Unit Director for Quentin Burdick Memorial Health Care Facility

Model Diabetes Programs

Development of the regional Model Diabetes Programs is a major achievement of the IHS National Diabetes Program. In 1979, following the recommendation of the National Commission on Diabetes, five model programs were incorporated into existing IHS sites at hospitals and clinics serving AI/AN communities. Subsequent legislation by Congress has enabled the IHS to increase the current number of Model Programs to nineteen. They are located in diverse settings in the 12 IHS Areas, from the Navajo Reservation to Alaskan villages; from an urban setting at Albuquerque Indian Hospital to a tribal consortium in northern Maine. The sites have been selected to represent a spectrum of facilities and settings (Appendix F).

The model programs are designed not only to expedite care and provide education to people with diabetes, but also to translate and develop new approaches to diabetes control that serve as models for other Indian communities facing similar problems. Their contributions to diabetes care in AI/AN communities are impressive:

- ! Model Diabetes Programs provide state-of-the-art, comprehensive clinical diabetes care using a multi-disciplinary approach to individuals, families, and communities served by the programs.
- ! Model Diabetes Programs offer diabetes education and nutritional counseling services to individuals and families on an inpatient and outpatient basis in clinics, homes, and within the community. These services include assessment and information sharing and specific interventions for pregnant women and persons with other health problems related to diabetes.
- ! Model Diabetes Programs provide professional education through conferences, workshops, and in-service settings and through articles in IHS and other American Indian tribal and urban publications.



I know that education is the key and we need more money for education. This wasn't done (education) in my younger time. I really didn't know what diabetes was, how it affects you in the later years. I guess if I had a little more education on it, I probably wouldn't be sitting here without my limbs.

Lawrence Bedeau, Red Lake Band of Chippewa, 55 years old,

- ! Model Diabetes Programs sponsor diabetes prevention activities, including screening programs, special events in Indian communities, exercise and physical activity programs, and school-based interventions.
- ! Model Diabetes Programs offer support and technical assistance to community health workers serving the elderly, school children, and others in diabetes and foot screening, blood sugar testing, physical activity, cooking, menu planning, and home visits.
- ! Model Diabetes Programs provide technical assistance to health units, local hospitals and clinics, police departments, firefighters, head start programs, casinos, senior programs, and

teen wellness centers on the tribal, IHS Area-wide, and national levels.

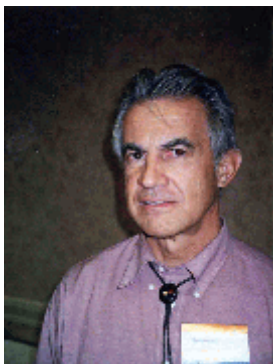
- ! Model Diabetes Programs develop, field test, and distribute culturally and literacy-appropriate diabetes educational materials, both written and visual.
- ! Model Diabetes Program staffs have written many scientific articles outlining their work in AI/AN communities that have been published in peer-reviewed medical journals.

Collaborations and Partnerships

Agencies and Organizations

The IHS National Diabetes Program offers diabetes consultation services to staff of medical facilities within the 12 IHS Areas that the Model Diabetes Programs do not reach. The national program also coordinates with other Federal and private agencies involved in diabetes-related programs such as the *Diabetes Prevention Program* and the *National Diabetes Education Program*, both funded by the National Institutes of Health (Appendix E). In addition, the IHS also participates with the:

- ! *Centers for Disease Control and Prevention, Division of Diabetes Translation*, in diabetes control and surveillance activities in AI/AN communities and on their *Translational Advisory Committee*
- ! The *Diabetes Interagency Coordinating Committee*, comprising diabetes representatives from all the Federal agencies
- ! The *President's Initiative on Eliminating Health Disparities - Diabetes Committee*
- ! *Association of American Indian Physicians, National Indian Health Board, Center for Native American Health, National Indian Council on Aging*, and other American Indian organizations
- ! American Indian subcommittee initiative of the *National Diabetes Education Program*, cosponsored by NIDDK and CDC



There are many talented people throughout Indian country working on progressive diabetes initiatives. If we are to deal effectively with this devastating epidemic, it is critical that we work collaboratively on these initiatives.

Dave Baldrige, Cherokee, Executive Director, National Indian Council on Aging

- ! *American Diabetes Association's* outreach initiative program for AI/ANs
- ! *State Department of Health Diabetes Control Programs*
- ! *Tribal Colleges and Universities*

Input from Tribal Communities

In all of its current activities, but especially since implementation of the *Grants for Special Diabetes Programs for Indians*, the IHS National Diabetes Program has taken advantage of opportunities to hear what tribal leaders have to say. The Program supported formation of the Tribal Leaders Diabetes Committee to have a means of seeking advice and guidance on issues of concern to tribes and tribal organizations. In addition, input from tribal communities is solicited to ensure that tribal and cultural concerns are addressed. Educational materials, treatment programs, nutritional counseling, and physical activities are all tailored to accommodate cultural, physical, and geographical considerations in diverse AI/AN communities.

In June 1997, the IHS cosponsored the Diabetes Future Search Conference to gain input on ways that AI/AN communities could capitalize on opportunities afforded by recent advances in diabetes management and control. Key participants in this conference included tribal leaders, people with diabetes, health care professionals, and others interested in diabetes in AI/AN communities. This conference established the need for continued discussions with tribal leaders and community members in identifying additional approaches and strategies needed for diabetes prevention and management in AI/AN communities.²



What we're doing here today as tribal leaders, we may never see the results of what we do, but . . . we are here for the future good of the tribes that we represent . . . How can we best do something for future generations? That's what we're here to talk about . . . There are some people that are already gone, we've lost them. But it's those that we can stop (from getting this disease) that we can help, we can talk about prevention. Those are the ones we need to be thinking about . . . that group of young people.

**Alvin Windy Boy Sr, Chippewa Cree, Councilman, Chair,
Tribal Leaders Diabetes Committee**

Scope and Impact: Diabetes Epidemiology

Prevalence of Diabetes

Diabetes has had a major impact on American Indians and Alaska Natives. In fact, in the last half of this century, the disease has reached epidemic proportions in AI/AN communities. Virtually unknown 50 years ago, type 2 diabetes (formerly known as type II or adult-onset, noninsulin-dependent diabetes) is now a severe health problem in every AI/AN community.

In 1996, nine percent of AI/ANs aged 20 years or older had diagnosed diabetes. On average, AI/ANs are 2.8 times as likely to have diagnosed diabetes as non-Hispanic Whites of similar age.³ In all 12 IHS Areas, diabetes is reported as one of the top 10 major health problems.⁴ In some tribes, notably the Pima Indians of Arizona, half the adults have diabetes,⁵ and the official rate of diabetes among Navajo Indians aged 45 or over is 40 percent.⁶ The actual prevalence of the disease may be one-third to one-half higher in many communities because of undiagnosed cases, as estimated by the American Diabetes Association.

Diabetes has had a major impact on American Indians and Alaska Natives.

- ! Nine percent of all American Indians and Alaska Natives twenty years or older have diagnosed diabetes.
- ! In 1996 American Indians and Alaska Natives twenty years or older were 2.8 times more likely to have diabetes as non-Hispanic Whites of similar age.
- ! In all IHS regions diabetes is reported to be one of the top ten major health problems.

The disease is also *increasing* in prevalence among all American Indian and Alaska Native populations. IHS studies show that between 1991-97, the prevalence of diabetes increased in all major regions served by the agency. The increases in prevalence ranged from 17 percent among tribes in the Northern Plains to 80 percent in Alaska.⁷ Two tribes in the Nashville Area, the Choctaw and Cherokee, had a 30 percent increase in diabetes prevalence in those 6 years.⁷ Earlier, in 1989, a survey among the Mississippi Choctaw showed that more than one-third of the 638 adults from ages 45 to 64 years had diabetes, and there were almost as many cases in the younger age group from ages 15 to 44 years.⁸

Overall, about 65,000 American Indians and Alaska Natives aged 20 years or older had diagnosed diabetes in 1996, according to IHS statistics.³ Almost half of all diabetes patients are between the ages of 45-64 years, and 25 percent are 65 years or older.³ American Indian and Alaska Native women 65 years or older have especially high rates: one in four has diagnosed diabetes.³ By comparison, in the U.S. non-Hispanic White population, 11.2 percent of women 65 years or older have diabetes (Table 1).³

Table 1. Prevalence* of diagnosed diabetes among American Indians/Alaska Natives† (AI/AN) and non-Hispanic Whites§ aged 20 years, by age and sex—U.S., 1996

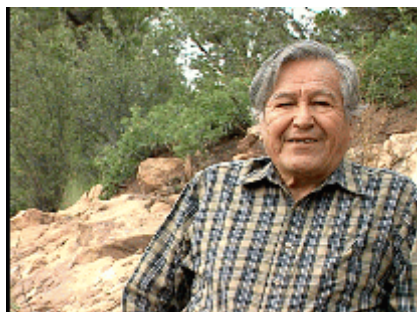
| Age group (yrs) | Men | | Women | | All | |
|-----------------|------------|---------------------|-------------|---------------------|------------|---------------------|
| | AI/AN | Non-Hispanic Whites | AI/AN | Non-Hispanic Whites | AI/AN | Non-Hispanic Whites |
| 20–44 | 3.1 | 0.6 | 3.8 | 1.3 | 3.5 | 0.9 |
| 45–64 | 16.7 | 5.4 | 21.1 | 5.1 | 19.0 | 5.2 |
| \$65 | 19.1 | 11.8 | 23.3 | 11.2 | 21.5 | 11.4 |
| \$20 | 7.7 | 3.9 | 10.1 | 4.5 | 9.0 | 4.2 |
| Age-adjusted¶ | 9.7 | 3.8 | 12.0 | 4.0 | 10.9 | 3.9 |

*Per 100 persons.

†American Indians/Alaska Natives in the 1996 Indian Health Service (IHS) Patient Care Component file; excludes data from 25 (representing 11% of the population served by IHS) of the 166 IHS service units because the data were incomplete.

§Non-Hispanic Whites in the 1995 National Health Interview Survey.

¶To the 1980 U.S.



Diabetes is incurable. But they can control it by eating the right kinds of foods, exercising, and these kind of things. These are individual kinds of things that a person has to do for themselves. I hear there is a program up in the Dakotas . . . where they are using medicine people who are knowledgeable in the use of herbs . . . and they are working with non-Indian doctors to turn around some of the problems with diabetes.

Jim Hena, Pueblo of Tesuque, former Tribal Governor

Trends in Diabetes Prevalence

Two alarming trends have recently become evident among American Indians and Alaska Natives. One is the rise of diabetes in Alaska Native people, as noted above; the other is the development of type 2 diabetes in younger American Indians. In the general population, type 2 diabetes usually develops after age 40.

Finding adolescents with type 2 diabetes in American Indian and Alaska Native communities is not uncommon. A recent IHS study shows **a steady increase in the rate of diagnosed diabetes in American Indian and Alaska Native adolescents and young adults** between the years 1991-97.

From 1991 to 1997:

- ! Among AI/AN adolescents age 15 to 19 years, diabetes prevalence increased by 32 percent;
- ! Among AI/AN young adults between 20 and 24 years, diabetes prevalence increased by 36 percent;
- ! Among AI/AN young adults age 25 to 34 years, diabetes prevalence increased by 28 percent.

At all age levels, the *increase* in diabetes prevalence was higher in young men, although the actual prevalence rate among women was still higher than among men. It should be noted that the study did not distinguish between type 1 diabetes and type 2 diabetes. (Type 1 diabetes usually develops in childhood and is considered rare in American Indian and Alaska Native populations.)⁷



And it's sad to say that we live in a push button age and the kids can't even empty our trash cans. They don't get exercise and they don't eat right . . . We can start at home, start teaching our young ones that are on the reservations all these things . . . all these values. Now all the young people know is a can opener. They don't know the basics of good potatoes and all the good vegetables.

Betty Thin Elk, Rosebud (Sioux), has had diabetes for 24 years

Etiology of Diabetes in American Indians and Alaska Natives

Much of our information about the nature and impact of diabetes in AI/AN communities ! indeed type 2 diabetes in general ! comes from ongoing cooperative studies with the Pima tribe. Since 1965, the NIDDK has maintained a facility at the Gila River Indian Community in Arizona to carry out studies with volunteers from the Pima community. These studies and data from other tribes show that the major factors contributing to type 2 diabetes in American Indians are obesity, especially central obesity (upper-body/above the waist obesity), genetics, and high levels of insulin in the blood, which results in insulin resistance, a forerunner of type 2 diabetes.

Contributing to obesity, particularly in the last half century, is adoption of a "westernized" high-fat diet by many AI/ANs. Dietary counseling is generally limited or not available on reservations. Often, access to quality foods, such as fresh fruits and vegetables, is scarce or available only at a great distance, and people on reservations must rely on commodity foods furnished by the Government, which are often high in fat and calories. The level of physical activity also has declined, with less reliance on hunting and farming as occupations and the adoption of more sedentary occupations.



The grandfathers and my grandmothers taught us things. They ate according to what they should eat, the Indian way, the traditional way. They taught us how to gather these foods and eat them. And they were strong . . . My grandfather, No Two Horn, was 107 when he died. And he had a cane but he used it just now and then. And he would take it and put it above his head and run in the mornings.

Zona Loans Arrow, Standing Rock Sioux, 72 years old, diagnosed with diabetes at age 34

The tendency to become obese appears to have genetic components, particularly in diabetes-prone families. Among some AI/ANs, obesity develops at an early age. Researchers have found that diabetes rates are highest in full-blooded American Indians, and a genetic marker linked with insulin resistance has been identified in the Pimas.⁹

Diabetes Mortality

According to statistics, diabetes mortality is more than 2 times higher in the American Indian and Alaska Native population than in the general U.S. population.⁴ However, the *actual* death rate attributable to diabetes among American Indians and Alaska Natives is believed to be 4.3 times higher than in the general population.¹⁰

Most experts agree that because of under-reporting on death certificates, true diabetes mortality is underestimated in national statistics. Also, Indian heritage is not always apparent on death certificates. Diabetes death rates in American Indians increased 550 percent in women and 249 percent in men over a 30-year period in New Mexico.¹⁰

Diabetes Complications

AI/ANs have higher rates of diabetes at all age levels, and they also have high rates of long-term diabetes complications, particularly kidney failure, blindness, and amputations. Because they tend to develop the disease earlier in life, compared to the general U.S. population, they also tend to develop these complications sooner.



I don't feel like there's anything wrong with my health right now but there has been. I have only one leg. I have a toe missing on the other side. I am blind. It's from diabetes, they told me.

Vern Antone, Kiowa

According to studies, rates of diabetes-related kidney failure in AI/ANs are six times higher than for the general U.S. population.⁹ High rates of kidney failure are reported in many tribes, including the Navajo, Cherokee, Sioux, Pima, Zuni, Chippewa, Oklahoma tribes, and Alaska Natives.⁹ From 1975-84, diabetic nephropathy (kidney disease) was the leading cause of nontraumatic death among the Pimas.⁹ Because few tribes have community-based dialysis centers, many AI/ANs living on reservations in remote areas do not have ready access to treatment centers. AI/ANs are also less likely than Caucasians to get a kidney transplant.

Diabetic retinopathy, which can lead to blindness, is also common in many tribes. Various studies among the tribes in Oklahoma and the Pima tribe in Arizona have shown rates ranging from 14 percent to 49.3 percent.⁹ In addition, AI/ANs have high rates of lower extremity amputations and foot ulcers and loss of sensory perception in the feet, which can lead to amputation. In addition, AI/ANs also develop high rates of diabetes-related periodontal disease and infections. One study in the Sioux tribe showed that those with diabetes were 4.4 times more likely to develop tuberculosis than those without diabetes.⁹

Demographics of American Indian and Alaska Native Communities

In 1998 the IHS had approximately 70,000 people with diagnosed diabetes listed in its computerized record system. Table 2 shows some characteristics of this population in 1998.

Table 2 **Demographic characteristics of people with diagnosed diabetes, *IHS Diabetes Care and Outcomes Audit, 1998***

| Gender | % | Duration of Diabetes | % |
|------------------------|----|--|----|
| Males (n= 4517) | 39 | Less than 10 years | 56 |
| Females (n= 7064) | 61 | More than 10 years | 33 |
| Age 15-44 years | 24 | Overweight (>85 th percentile) | 67 |
| 45-64 years | 51 | Obese (>95 th percentile) | 43 |
| 65+ years | 23 | | |

According to the most recent census figures, as of September 1, 1999, 2.4 million American Indians and Alaska Natives live in the United States.¹¹ There are more than 550 federally recognized tribes, with differing languages and cultural backgrounds. The lives of AI/ANs have



I didn't have any inkling of what a diabetic was . . . so that went on like that 'til my eyesight was failing. And so they corrected that by laser treatments and I started getting bigger doses of insulin . . . But as the years went by and I didn't take care of myself . . . I had congestive heart failure and that was caused by diabetes . . . That was in August. By October 3, I was on dialysis.

Betty Thin Elk, Rosebud (Sioux), has had diabetes for 24 years

changed radically in this century. Today, according to IHS and CDC statistics, about 38 percent live on reservations, about 22 percent live near reservations, and approximately 40 percent live elsewhere in the United States. More than half, about 1.46 million, live in reservation States served by IHS facilities.⁴

Economically, AI/ANs are among the country's most disadvantaged populations. More than 30 percent (31.6 percent) live below the poverty level, compared to 13 percent of the general population, and they are more than twice as likely to be unemployed (2.5 times for men and 2.2 times for women).⁴ Their median income is two-thirds that of the rest of the country, and the high school dropout rate is reported to be 35 percent, compared to a dropout rate of 25 percent in the general U.S. population.⁴ They are a young population, with a median age of 27.7 years, compared to 35.5 years in the general population, and 33 percent are below the age of 15.¹¹ Their life expectancy is below the national average.⁴



I wish there was a way we could have an interpreter . . . or it could be written in Indian . . . there are so many things we don't understand. We don't all read the books that's given to us. We don't understand what its all about . . . If somebody explained to us how to take care of each other, it could help.

Candelaria Valencia, Elder, Pueblo of San Felipe

History of the Grants Process

Tribal Consultation

The legislation authorizing new grants for diabetes prevention and treatment activities in AI/AN communities sparked an intensive, indepth tribal consultation process to explore the best method for allocating the new resources and to develop recommendations. To expedite the distribution of these new funds to local Indian health programs, the IHS convened a series of meetings in the fall of 1997.



I am chairman of the National Indian Health Board, we advocate for all 550 tribes. I am diabetic . . . I challenge each of you to get involved. We have a serious issue in our community and nationally. We can beat this real serious disease by working together.

If we want to be sovereign, we need to take care of ourselves . . . We have to improve our shared efforts among our communities . . . with IHS, NIHB, NICOA and other Indian organizations.

Buford Rolin, Poarch Band of Creek Indians, Councilman, Chairman, National Indian Health Board

Diabetes Workgroup

The consultation process began in September at the NIHB National Consumer Conference in Spokane, Washington, with elected representatives from tribes, urban Indian health organizations, and IHS officials. One purpose of the meeting was to announce the new grants program and to solicit the views of elected tribal and urban Indian health program leaders. Regional caucuses in all 12 IHS Areas followed this meeting to develop recommendations for the *Special Diabetes Programs for Indians*.

Early in November of the same year, Michael H. Trujillo, M.D., M.P.H., M.S, Assistant Surgeon General and Director of IHS, named a workgroup to review recommendations from the Area caucuses, identify national allocation issues, and recommend policy options for the final decision-making process. The Indian Health Diabetes Workgroup consisted of 13 members, including two representatives from each of the following:

- ! National Indian Health Board
- ! Tribal Self-Governance Advisory Committee

- ! Urban Indian health programs
- ! IHS American Indian Physicians

Others in the workgroup included a member of the Association of American Indian Physicians, a diabetes expert, and three other elected tribal leaders.

The Workgroup met on November 19, 1997, to review background information from the tribes compiled by NIHB and to begin planning. It met again on December 15-16, 1997, to formulate final recommendations. Time was allowed between the two meetings for tribal councils in each IHS Area to submit their recommendations for the grants program and for allocation of funds at the Area level. The Workgroup's final recommendations for the *Grants for Special Diabetes Program for Indians* were presented to the Director of IHS on December 16. The Director issued his final decision on January 8, 1998, the details of which were announced at the combined Annual Meeting of the National Councils of Area Directors and Clinical Directors in Phoenix, Arizona.

The consultation process involved the full participation of tribes, urban Indian organizations, and IHS staff regarding the development of the program and the most equitable distribution of funds. The recommendations developed by the Workgroup reflected the majority opinion based on input from tribal organizations throughout the Nation. In his final decision, the Director approved all of the Workgroup's recommendations, making only one change in the formula for determining allocation of funds.



Education is the biggest part of dealing with diabetes. Getting the people to understand and it's their own native people that's going to have to educate us. If somebody comes from off the reservation I guess they don't take them seriously.

They just don't take the disease seriously and I went through the same thing. I didn't take it seriously until it really started affecting me. It affects all parts of the body . . . And I thought it would go away sometime just like a common cold but I guess I was wrong and it didn't go away.

Lawrence Bedeau, Red Lake Band of Chippewa, 55 years old, diagnosed with diabetes in 1974

Implementation Guidelines for the Grant Program: Director's Final Decisions

The recommendations developed by the Workgroup and approved by the Director, IHS, for implementing the program were as follows:

Distribution Formula

- ! The grant funds were allocated to IHS Areas according to an agreed-upon formula. Each Area would then determine grant program design and distribution of funds within its region.
- ! The grants were to be awarded on a noncompetitive basis.
- ! The sum of \$1.5 million was set aside each year for urban Indian health programs.
- ! For the first year of funding, the formula for determining each Area's allocation was based on user population (30 percent); disease burden as measured by excess diabetes prevalence and mortality (52.5 percent); and tribal size adjustment, to compensate for smaller-sized tribes (12.5 percent). In addition, the Director set aside \$116,000 (5 percent) per Area to improve data and reporting systems. (Appendix B)
- ! A cap of 1 percent was placed on administrative costs.
- ! For Year 1, all grant funds were to be awarded by June 1, 1998.

IHS and Tribal Roles

- ! The participation of the IHS Model Programs in the *Grants for Special Diabetes Programs for Indians* would be determined at the Area level.
- ! Tribal governments would decide how the monies were to be divided among programs within the IHS Area. Individual grant sites decided the focus and chose particular primary, secondary, and tertiary prevention strategies for diabetes, depending on needs and priorities in their community.
- ! Authority and responsibility for program evaluation was assigned to local and Area leadership as well as IHS Headquarters, consistent with IHS principles, using existing IHS guidelines for data collection.
- ! The IHS was to work with CDC in initiating a tribal consultation process on issues relating to diabetes in AI/AN communities and the Diabetes Prevention Research Center.

Diabetes Prevention Research Center

- ! For each of the 5 years, \$1 million was to be set aside for a Diabetes Prevention Research Center to be located in Gallup, NM. The Center would eventually serve all tribes and support primary, secondary, and tertiary prevention research.

- ! The Workgroup recommended that a Tribal Advisory Committee be established to provide advice and consultation to the Center. The IHS Director and the Workgroup supported collaboration with the CDC to obtain input and guidance from representatives of IHS, tribal, and urban Indian organizations nationwide in the Center's design, operation, and future expansion.

In summary, the total amount of funds available in the first year of the *Grants for Special Diabetes Programs for Indians* was \$33 million. Of this sum, \$1 million was set aside for the National Diabetes Prevention Research Center and \$1.5 million for urban Indian health programs. In addition, \$300,000 was allowed for administrative costs, leaving \$30.2 million for the distributions as grants (Appendix C).

These funds were allocated to the 12 IHS Areas according to the formula recommended by the Diabetes Workgroup to the Director, IHS. Figure 1 shows how the formula works.

Special Diabetes Programs for Indians Grant Distribution Formula - Year 1

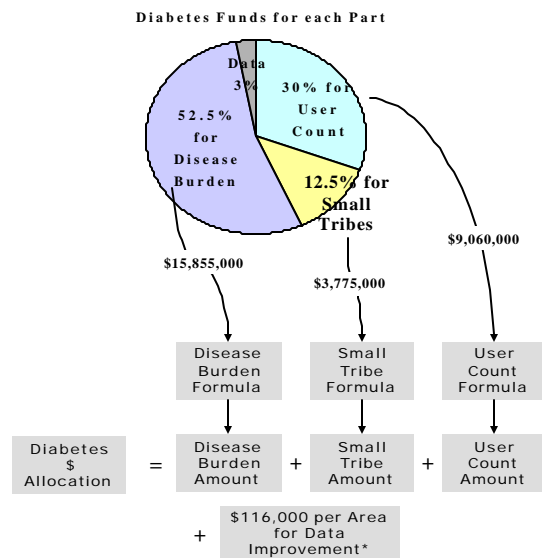


Figure 1

Tribal Leaders Diabetes Committee

The *Tribal Leaders Diabetes Committee* (TLDC) was established in 1998 by the Director of the IHS in response to the successful partnership between IHS and tribal leaders in deciding the process for distribution of the Balanced Budget Act of 1997 *Special Diabetes Program for Indians*. In creating this permanent committee, the Director sought to foster an ongoing dialogue between the agency and tribal leadership on matters related to diabetes in AI/AN communities. The TLDC is comprised of one elected tribal official from each IHS Area and 2 members-at-large. The Chief Medical Officer, Dr. Kermit Smith of the IHS and one elected tribal leader, Councilman Alvin Windy Boy Sr, serve as Co-Chairs of the committee. The TLDC meets quarterly with intermittent conference calls as needed between meetings. The agenda is established jointly by the IHS National Diabetes Program, the Grants Management Office and the tribal leaders, based on current issues and concerns.

The impact of this relationship on the grants process is evident in the unique character of the grant program and its clear attention to tribal concerns. Tribal leaders' involvement in the grants process has allowed the IHS National Diabetes Program greater access to, and increased awareness and knowledge of, tribal concerns across the nation. This valuable collaboration between the IHS and tribal leaders has been an unexpected, but very important, outcome of the *Special Diabetes Program for Indians*, and has contributed significantly to the success achieved in Indian communities thus far.

I see here it says Native Americans are minority populations . . . We try to stress the fact that we are tribal governments and tribal nations. We always stress our government-to-government relations, we have to do that.

**Patricia Martin, Yakama Nation, Councilwoman, Portland Area
Representative to the Tribal Leaders Diabetes Committee**

Area Consultation

Following the January 1998 meeting at which the Workgroup's recommendations and the Director's decisions were presented to tribal Indian health representatives, the consultation process moved to the Area level. Each Area held tribal caucuses to identify programs eligible to apply for grant funds. Each Area was required to submit a report to the Director of IHS identifying eligible programs and the amount of funding for each. The Director also asked the Areas to document the tribal consultation process used to ensure that it had been fair and

representative. To promote coordination of a range of diabetes services within an Area, Urban Indian health programs were encouraged to participate in the caucuses. Urban programs, however, were not eligible for Area funds since they were funded separately.

Elected tribal leaders should have a say in what happens to our health care because it affects our people . . . We can't forget those we work for . . . The agency did a good thing to ask tribal leaders to advise on these diabetes funds . . . I'd like to recognize IHS for involving tribal leadership in diabetes grants program in a way that has been far too absent over the course of time.

**Alvin Windy Boy Sr, Chairman, Tribal Leaders Diabetes Committee
Chippewa Cree Tribe, Councilman**

Grant Application

The IHS Grants Management Branch mailed grant application kits to all IHS and identified tribal health programs in the Area caucuses. Potential grant sites submitted applications in March and April. Each Area Chief Medical Officer and/or Area Diabetes Consultant reviewed the grant applications, rating them as acceptable, not acceptable, or as needing revisions. All sites were offered technical assistance in the development and revision of their applications. Awards were completed by June 1.

All together, the IHS awarded grants for 318 programs in the 12 IHS Areas serving American Indians and Alaska Natives.



When we did research for the grant we found there were four areas that weren't properly addressed: optometry, foot care, education with youth and (hiring) staff to assist with the Diabetes Program. With our new program we can treat our people properly, modify their shoes so their shoes fit correctly and we avoid amputations.

Anita Blue, Director of Economic Development and Tribal

Program Challenges

There were many challenges and obstacles making implementation of this grants program difficult. The IHS had gone through many changes in the several years before the *Special Diabetes Program for Indians* that influenced the way decisions were made regarding the grant program. Other challenges presented themselves as IHS carried out these decisions.

- ! Agency downsizing had a significant impact on the number of employees at Headquarters. At one time, the IHS National Diabetes Program had as many as 13 employees. When Congress announced the Balanced Budget Act (BBA) funds for diabetes, the program had five employees and no director.
- ! An increase in self-governance activities had occurred over several years before the BBA. Many tribes were using the compact and contract possibilities made available through P.L. 638 legislation to take over and run their own health care systems. The grant program had to take into account these mechanisms for funding, although the grants program came through the BBA, and thus was subject to different regulations than self-determination contracting/compacting authorized by P.L. 93-638.
- ! The IHS Grants Management Branch had never managed a grant program of this magnitude. The software system used to monitor IHS grants was obsolete and needed replacement.
- ! The BBA also provided an opportunity to address Medicare reimbursement for diabetes education training services. This added a significant amount of work to an already reduced staff at the IHS National Diabetes Program.
- ! The grants process requires that agency personnel serve as project officers to monitor the grants. The IHS National Diabetes Program did not have adequate personnel to serve this



These myths and old wives' tales that they had about diabetes, they're finding out are not true . . . They can do something about their disease. It takes a team of us to really work.

Diane LaFontaine, Diabetes Coordinator, Quentin Burdick Memorial Health Care Facility, 1,060 patients on diabetes registry

function. Instead, the Director decided to assign this duty to the Chief Medical Officers and Diabetes Consultants in each Area. Many did not have Project Officer training so this training had to be arranged quickly in several sites.

- ! More than half of AI/ANs live in urban Areas, away from their reservation, without access to IHS or tribal health care systems. Thus, many AI/ANs with diabetes have inadequate resources to address diabetes care and education.
- ! Final decisions on the grant process were based on the recommendations of tribal leaders, Urban Indian organizations and IHS staff. Allowing time for these recommendations to be formulated created delays in making the many decisions required by the grant process.
- ! Grant award dates varied among eligible tribes. Many tribes wanted to extend Year 1 awards to match their fiscal years. This would allow for increased quality in fiscal monitoring. Adjusting for this option increased the workload for the IHS Grants Management Division and created further challenges in grant reporting requirements.



I'm the cook of the house and so all my family went on the diet with me and that's very encouraging for them to do that . . . you need your family to back you. You know that you are not standing alone . . . you know someone cares.

My grandmother used to say that a long time ago we ate off the wild . . . We have a lot to teach our grandchildren, especially those of us who can talk and read and write in our own language . . . My grandmother used to say that we had to work for our eats . . . We carried water, we chopped wood . . . It wasn't a hardship for us because that's the way we lived. We were healthy because we were doing all this.

Betty Thin Elk, Rosebud (Sioux), has had diabetes for 24 years

Grants Program Baseline Information

Overview

The legislation authorizing the *Grants for Special Diabetes Programs for Indians* appropriated a total of \$150 million over a 5-year period. Additional funds from the Interior Appropriations Act in FY 1998 brought the total amount of funds available in the first year of the program to \$33 million. The total amount of money available for distribution to grant sites during the first year of the grant program was \$30.2 million, because of the funds set aside for Urban Indian programs, the National Diabetes Prevention Center, and administrative costs.

The legislation authorizing the *Grants for Special Diabetes Programs for Indians* specified that the monies were to be used to support diabetes treatment and prevention programs. Acceptable activities included primary, secondary, and tertiary diabetes prevention and treatment programs and related data collection. Grants under the program were for 5 years, with annual renewals, and covered both direct and indirect costs (Appendix C).

Request for Application (RFA)

The IHS RFA for the *Grants for Special Diabetes Programs for Indians*, dated February 4, 1998, was developed by the IHS National Diabetes Program and the IHS Grants Management Branch.¹² The RFA included complete instructions and background materials needed to apply for non-competitive grants authorized by the Balanced Budget Act of 1997 and by the FY 1998 additional appropriations made available through the Interior Appropriations Act. The RFA stated that the funds were “to provide diabetes prevention and treatment services for AI/ANs.”

Types of programs eligible for grant funds included:

- ! IHS programs, both inpatient and outpatient facilities;
 - ! Tribal health programs operating under a contract, grant, cooperative agreement, or compact with the IHS under the Indian Self-Determination Act; and
 - ! Urban Indian health organizations, including those functioning under a grant or contract with the IHS under Title V of the Indian Health Care Improvement Act, Scope of Grant Programs.
-

Narrative

The narrative section of the RFA gave applicants directions related to the following:

- ! Proposed project description
- ! Documentation of work plan and timeline
- ! Target audience descriptions
- ! Identification of partnerships or collaborations
- ! Descriptions of evaluation measures and data sources
- ! Identification of key personnel, including consultants and contractors
- ! Program budget estimates.



I went to the training sessions . . . I didn't understand, at first--it takes you a little while--just exactly what foods make your sugar go up and what foods you can eat to keep it down.

And I do feel much better if I take care of myself. If I'm not takin' care of myself, I don't feel good. And I don't feel like playing with my grandchildren or interacting with other people. I couldn't believe how much better I felt after I got it under control and how much better my eyesight was.

Dean McManus, Chickasaw, diagnosed with diabetes in July 1995

Appendices

Several appendices were included in the RFA, to facilitate the application process and provide ideas for programs:

- ! Diabetes prevention and treatment programs
- ! Resources for data collection in primary, secondary, and tertiary prevention
- ! Descriptions of the 19 Model Diabetes Programs with contact sources
- ! Detailed bibliography listing educational and program resources
- ! Description of and guidelines for the *IHS Diabetes Care and Outcomes Audit*
- ! Copies of the PHS Grants Policy Statement and Allowable and Unallowable Costs
- ! IHS Area Diabetes Consultant Directory

Reporting Requirements

General Requirements

The grant RFA outlined specific annual reporting requirements for each program. All grant recipients were required to submit a yearly progress report. Included in the progress report is general information on program accomplishments, as well as challenges and problems in achieving program goals and objectives.

All grant recipients were required to submit an annual progress report detailing:

- ! Program accomplishments
- ! Problems and challenges
- ! Required data elements
- ! Financial status

Data Elements

Each grant site was required to submit identified data elements that would measure and evaluate the overall *Grants for Special Diabetes Programs for Indians*. All sites must provide data annually on the prevalence of diabetes. Additional data elements would also be required:

- ! Number of diabetes related amputations
- ! Cases of end-stage renal disease
- ! Laser treatments for retinopathy
- ! Obesity prevalence of youth age 2-3 years, 4-6 years, and 13-15 years.

The IHS National Diabetes Program gave grant sites the option to choose the additional data elements they would report in Years 2 and 3. The number of additional data elements increases annually, from one in Year 2 to two in Year 3. By Year 4, grant sites must provide measures for all data elements.

In addition, grant recipients must provide data specific to the type of project they are conducting. For example, if the purpose of a primary prevention project is to prevent the later development of diabetes in women with gestational diabetes, grant sites should provide information on the number of mothers counseled, number of counseling sessions, and on the incidence of diabetes in the target population.

Reporting Requirement Options

In Year 1, many grant recipients requested that their individual renewal dates be made consistent with the Federal or tribal fiscal year cycle. This required a change in their continuation application dates. The change in application dates would allow better fiscal management and tracking at the individual sites. Yet, many programs also reported that these changes in the grant cycles, as well as the delays in Year 1 grant awards, created significant data collection and reporting problems. Sites also reported significant limitations in their infrastructures and capacity to conduct quality diabetes surveillance on the complications measures required in the RFA.

In response to these concerns, the IHS Grants Management Branch agreed to offer six different cycles for extensions and renewals of grant applications. To address the data and surveillance problems raised, the IHS National Diabetes Program added an optional grant reporting requirement. As an alternative to reporting diabetes data elements (amputations, end-stage renal disease, retinopathy, obesity), programs were given the option to provide the 87 data elements from the *IHS Diabetes Care and Outcomes Audit*. Those sites without a clinic-based program can provide data from the diabetes audit done at their local IHS or tribal clinic. This reporting option will allow all grant recipients an opportunity to provide valid data elements related to the diabetes care and outcomes within their communities.



... with our Diabetes Center of Excellence, we have tried to get out of the bricks and mortar of the hospital. We need to be out in the community to involve the people and get them doing things that are part of the wellness program.

Ray Grandbois, Turtle Mountain Band of Chippewa, Service Unit Director for Quentin Burdick Memorial Health Care Facility

Year 1 Grant Application Review

Review Process

Although the grants were noncompetitive, and not ranked or rated, the Grants Management Branch of IHS reviewed all applications for eligibility and compliance with the grant announcement. The applications were also reviewed by the Chief Medical Officers and Area Diabetes Consultants in each IHS Area Office. Grant application reviews addressed the soundness of proposed services, their compliance with the legislation and grant regulations, and recommendations on proposed costs. If the reviewers decided that the proposal needed revisions, the Area Diabetes Consultant was available to provide technical assistance.

Year 1 proposals were analyzed in terms of the following:

- ! Program emphasis
- ! Target population groups
- ! Screening, treatment, and prevention services
- ! Education
- ! Nutrition
- ! Physical fitness activities
- ! Health systems development components

In response to the RFA, the IHS awarded grants in Year 1 by June 1, 1998. Grants were awarded to 318 programs under 286 administrative organizations within the 12 IHS Areas. There were 27 grants awarded to IHS programs, 33 grants awarded to urban programs, and 258 distributed to tribal programs (Appendix A). The range of services and activities outlined in the grant applications reflects the widespread recognition of the critical need to address the epidemic of diabetes in AI/AN communities.



If I had a magic wand, I would . . . expand the center and add a physical therapy room. That is the only thing that is hindering our programs -- to have a formal type of exercise program.

Emily Velasquez, Senior Program Director, Pueblo of San Felipe

Year 1 Grant Application Analysis

The IHS National Diabetes Program carried out an analysis of the Year 1 grant proposals to determine the scope of activities proposed by the applicants and to establish baseline parameters for later comparison. The following shows the results of the Year 1 analysis.

Program Emphasis

The four Areas of program emphasis addressed by grantees in the initial *Special Diabetes Programs for Indians* were: planning, primary, secondary, and tertiary prevention (Figure 2).

- ! 67% of sites included elements related to the primary and secondary prevention of diabetes and its complications.
- ! 41% emphasized program planning.
- ! 32% included screening and treatment services for complication (tertiary prevention)

Because many programs chose to focus on several levels of prevention, the percentages exceed 100 percent.

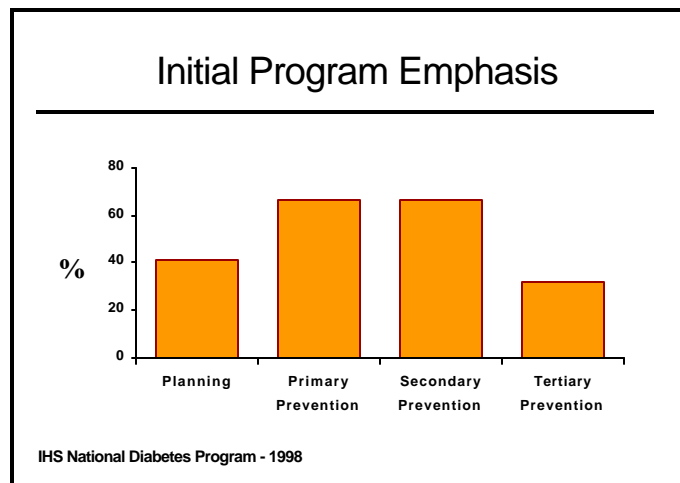


Figure 2

Figure 3 shows the distribution of these program emphases among IHS, tribal, and Urban Indian (I/T/U) grant programs.

- ! A greater number of Urban programs focused on planning. Many Urban programs were without diabetes programs when these grants became available.
- ! Many IHS facilities had diabetes activities in place when the grants were awarded. This is reflected in less need for planning and greater activity in diabetes prevention.
- ! Many IHS facilities are able to offer more tertiary prevention services than Urban sites and tribal health facilities are able to provide.

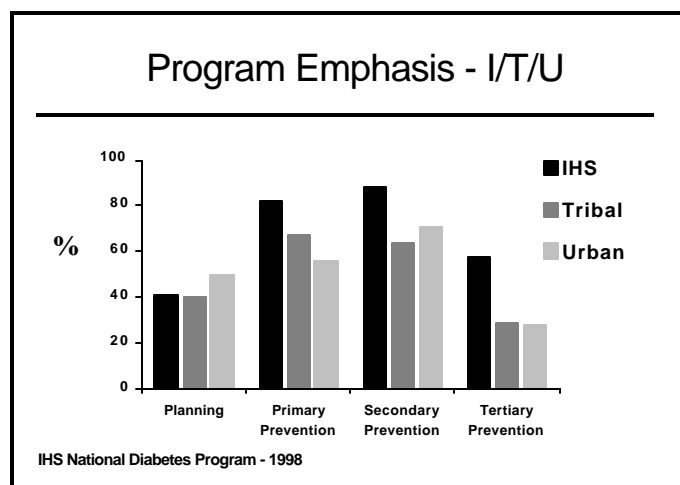


Figure 3

Target Audiences

Many grant programs targeted persons especially vulnerable for developing diabetes. Figure 4 shows this distribution:

- ! 18 percent focused on pregnant women with diabetes.
- ! 13 percent emphasized programs for children born to women with diabetes.
- ! 38 percent of programs have a major emphasis on family members of people with diabetes.
- ! 42 percent of programs proposed community-wide diabetes awareness activities.
- ! Nearly 20 percent of programs target high risk for diabetes, in general.

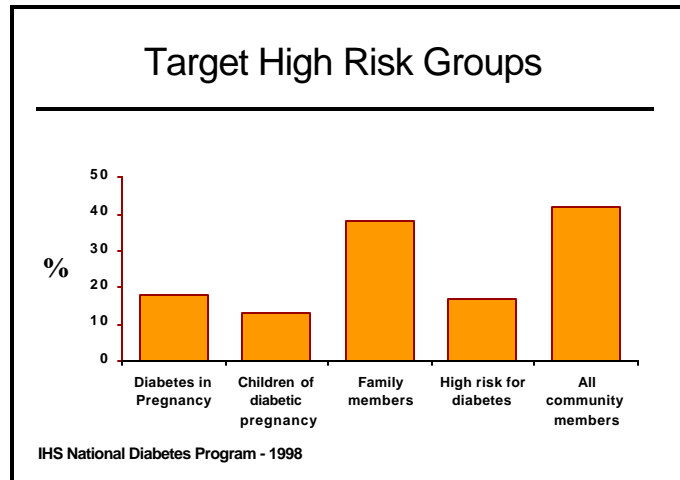


Figure 4

Most grant programs also planned programs for young people, especially children and teenagers. Figure 5 shows this distribution:

- ! 38 percent of programs proposed activities directed to elementary school students.
- ! 35 percent of programs focused on adolescents.
- ! 22 percent of the programs targeted children in Head Start.
- ! 12 percent of the programs placed an emphasis on young adults.
- ! 3 percent of programs included infants.

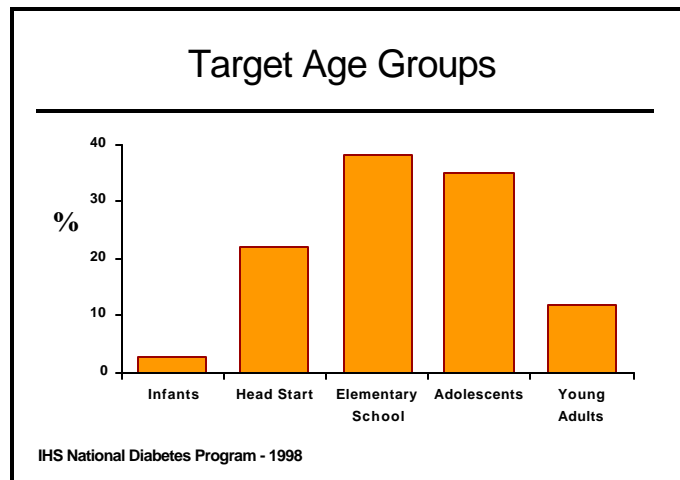


Figure 5

Many programs for children and adolescents were designed to teach awareness of the health dangers associated with obesity, to improve dietary habits, and to encourage physical activity.

Screening, Treatment, and Prevention Activities (Figure 6)

- ! Almost half (45%) of the proposed grant programs incorporated screening for diabetes.
- ! Many others also proposed to offer foot screening (42%), eye screening (28%), tests for kidney disease (20%), and screening for heart and vascular disease such as monitoring blood pressure and lipid levels (16%).

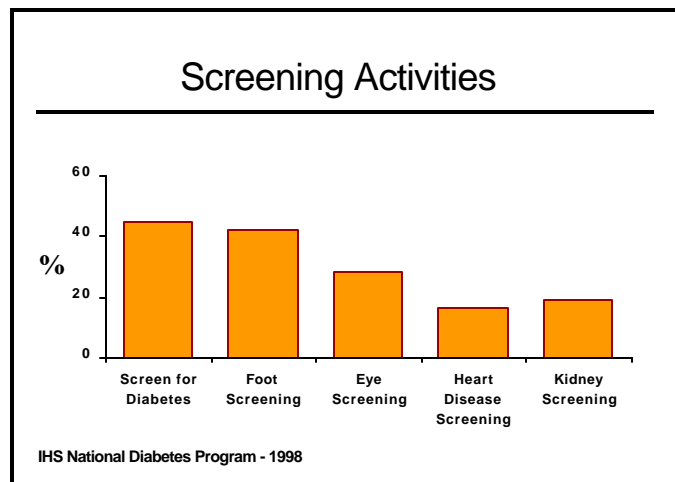


Figure 6

Diabetes Prevention and Treatment

Preventive and treatment services proposed by the programs target all of the major complications associated with long-term diabetes (Figure 7).

- ! 31% of the programs proposed special services to reduce amputations.
- ! 13% proposed to offer treatment and prevention services for kidney disease.
- ! 17% included treatment services for eye disease.
- ! 10% addressed heart and vascular problems.
- ! 6% proposed to provide dental care services.

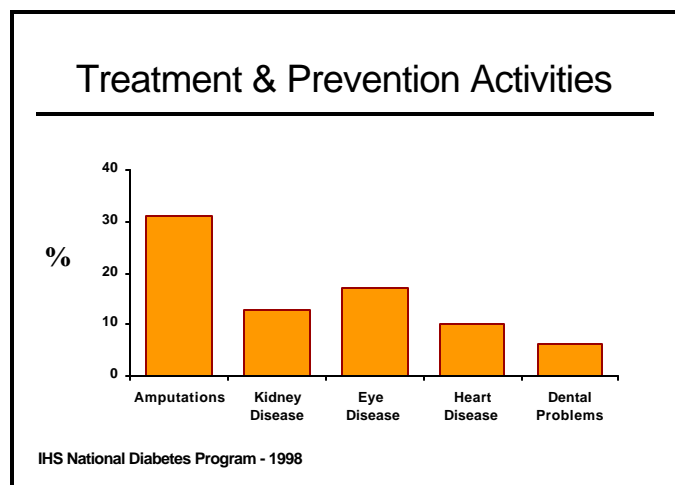


Figure 7

Diabetes Education

The importance of diabetes education for both public and patient audiences is evident in the emphasis placed by many programs on this area (Figure 8).

- ! More than half of the programs (53 percent) proposed to include community-wide education activities.
- ! 21 percent proposed school-based education programs.
- ! Almost half (47 percent) mentioned one-on-one patient education services, and 28 percent proposed to reach out to family members.
- ! 37 percent of the programs proposed to provide professional education for health care providers.

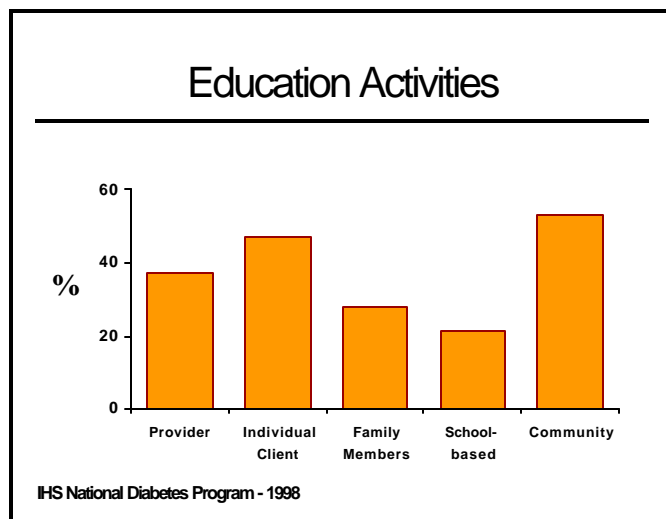


Figure 8

Physical Activity

Many programs stressed physical activity as shown in Figure 9.

- ! 21 percent of the programs proposed classes to promote physical fitness.
- ! 18 percent of the programs proposed individual training.
- ! 17 percent intended to use grant funds to purchase exercise equipment.
- ! 6 percent proposed programs to train exercise instructors.

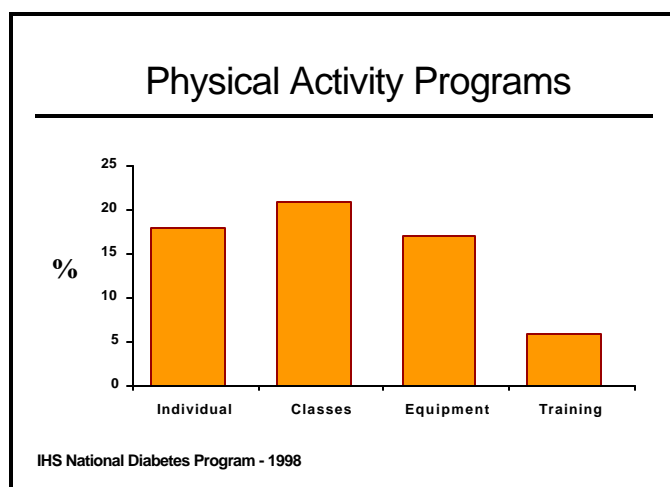


Figure 9

Nutrition Education

Most programs proposed an emphasis on nutrition education (Figure 10).

- ! 38% planned to offer group classes.
- ! 26% planned individual instruction.
- ! 6% proposed nutrition training sessions for health care staff.

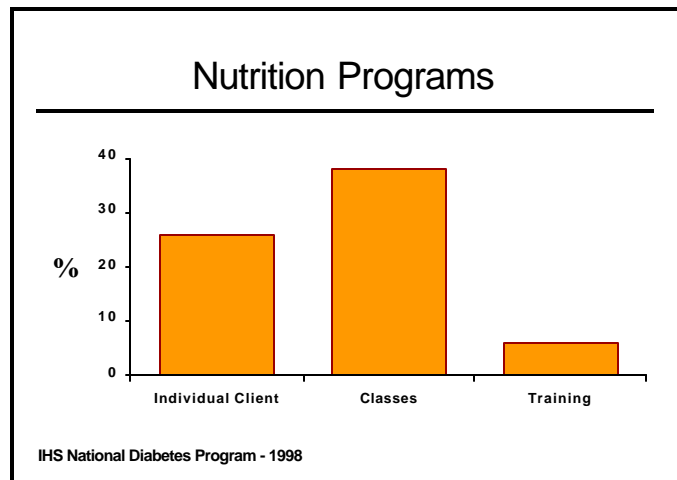


Figure 10

Health Systems Development

Most of the applications included elements related to improving diabetes-related health systems and services in tribal and Urban Indian communities (Figure 11).

- ! 72 percent proposed to use grant funds to hire personnel, underscoring the critical shortage of diabetes care professionals in AI/AN communities.
- ! 52 percent of the proposals cited the need for surveys to improve data systems.
- ! 51 percent proposed to establish diabetes registries to assess and track the people with diagnosed diabetes in their communities.
- ! It is now well recognized that optimum diabetes care involves a team approach that includes at least a physician, nurse educator, and dietitian. 39% of program proposals included funds to support this level of care in their facilities. Other health systems development activities were directed to improvement or expansion of diabetes clinic services (37 percent).

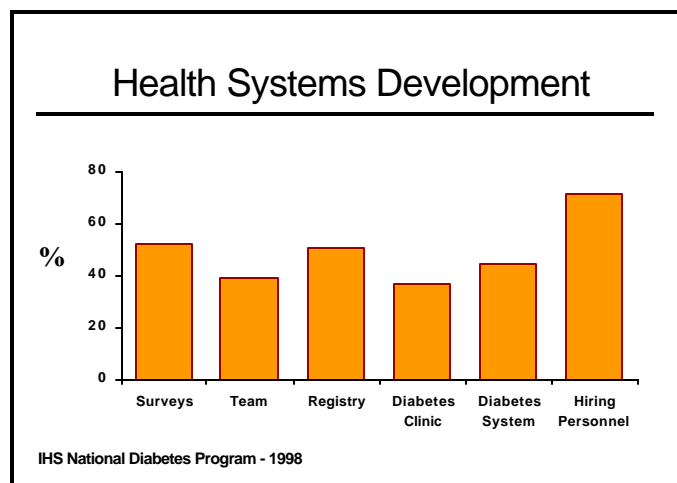


Figure 11

Enhancement of diabetes systems that includes referral patterns for specialty care, patient follow-up, and provision of ancillary services such as laboratory and pharmacy services were proposed by 45% of program.

Analysis of Current Grant Program Activities

Introduction

Recognizing that the use of diabetes surveillance statistics alone would not reflect the magnitude of changes happening in Indian communities as a result of the *Special Diabetes Program for Indians* grant funds, the Indian Health Service decided early on to use a variety of evaluation strategies. The results presented in this section represent the first set of data collected about the grant activities since the initial grant proposals. The purpose of this evaluation strategy was to assess successes and barriers and to ask specifically what changes had occurred in American Indian and Alaska Native communities after two years into this grant program.

Method

In Fall 1999, the IHS National Diabetes Program commissioned Macro International Inc., a consulting firm with diabetes expertise used frequently by the CDC and NIH, to collect information from the grantees as part of the grantees' annual reporting process. Packets describing the intent for collecting the information and the types of information desired were sent to all 318 grant delivery sites in early September 1999.

By the end of October, 1999, 277 service delivery sites (83 percent) responded with information about the following:

- ! Special emphases of their grant program and intended impact
- ! Age groups and special high risk target groups served
- ! Methods used and groups targeted for: screening, diabetes education, physical activity, and nutrition
- ! Service areas improved or enhanced because of the grant funds
- ! Program infrastructure improved or enhanced because of the grant funds
- ! Staffing needs

Findings

Analysis of these data was completed in November 1999. Highlights of the analysis are presented below:

Program Emphasis on Target Age Groups

Grant programs emphasize all ages but particularly adults and the elderly (Figure 12).

- ! Eighty percent or more of all programs have a major focus on elders (>55 yrs) and adults (26-54 yrs).
- ! Approximately half (50.2%) place strong emphasis on young adults (18-25 yrs).
- ! 36% increased their focus on adolescents, 27% on elementary school age, and 19% on preschool age, and less than 4% on infants.

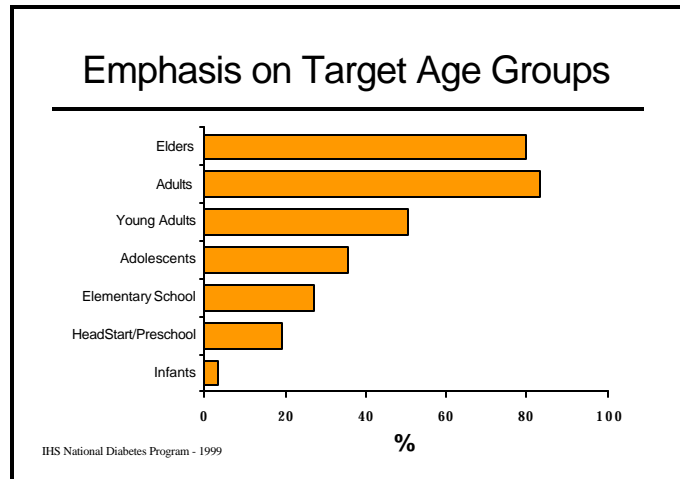


Figure 12

Change in Focus on Target Age Groups: Elders and Adults

Programs are doing significantly more with almost all the target age groups since they received the grant funds (Figure 13).

- ! Over 75% of programs indicated they are focused more on elders (78.7 percent), and adults (86.3 percent).
- ! 68% have more focus on young adults as a result of the grant funds.

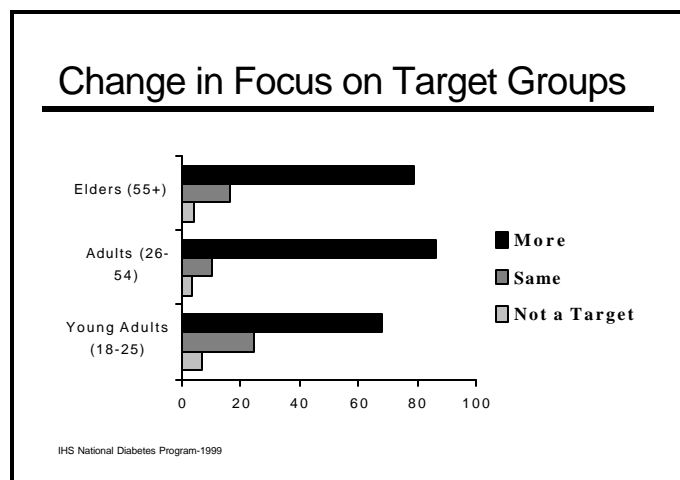


Figure 13

Change in Focus on Target Age Groups: Children and Adolescents

Programs have increased their focus on children and adolescents as a result of the grant funds (Figure 14):

- ! 55% more focus on adolescents.
- ! 42% more focus on elementary school age.
- ! 33% more focus on preschool age.

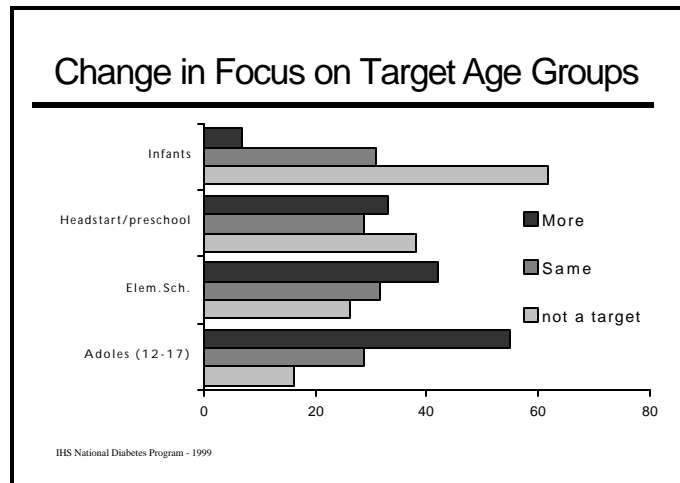


Figure 14

Emphasis on High-Risk Groups

Programs emphasize a variety of high-risk groups, both those with diabetes and without (Figure 15):

- ! 79.8% of programs focus on overweight clients with diabetes.
- ! 78.7% of programs focus on people with high blood pressure who also have diabetes.
- ! 50.3% of programs focus on people with diabetes who use tobacco.

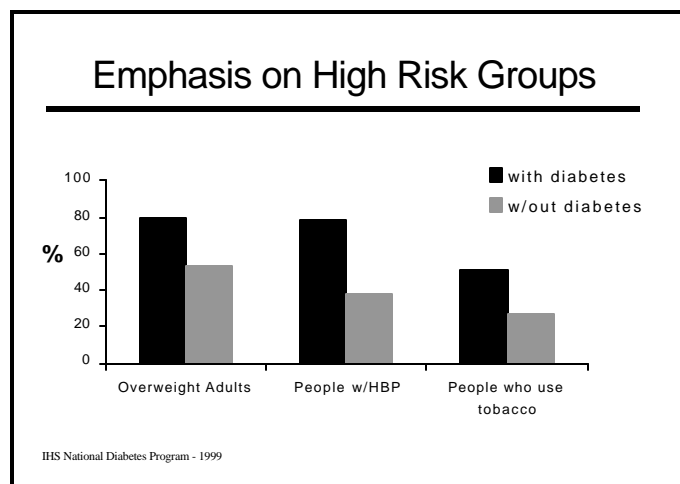


Figure 15

Change in Focus on High-Risk Groups

Programs have increased their focus on many high-risk groups since receiving the grant funds (Figure 16). As a result of grant funds:

- ! Three-fourths of programs now focus more on clients with newly diagnosed diabetes (75.8%).
- ! Over two thirds of grant programs focus more on family members of people with diabetes (68%).
- ! Over one-third focus more on pregnant women (37.2%) as a result of the grant funds.

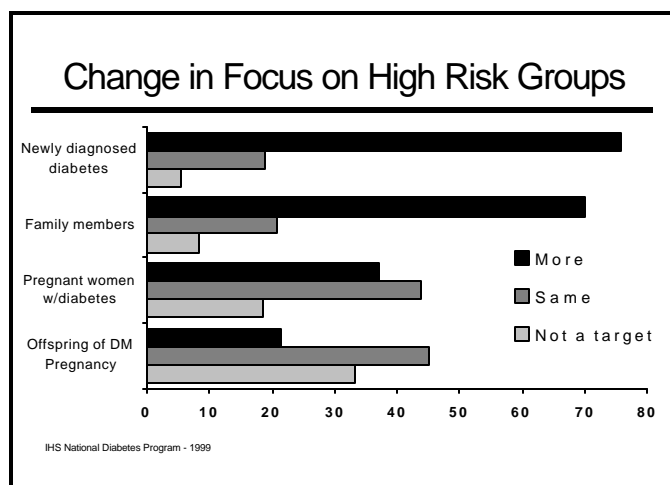


Figure 16

Change in Focus on High-Risk Groups

Programs have increased their activities to reach out to many groups at high risk for diabetes as a result of the grant funds (Figure 17). As a result of grant funds:

- ! Over two thirds of programs now put more emphasis on adults who are overweight (71.5%) and people with high blood pressure (70%).
- ! Over one half of programs now have more emphasis on children who are overweight (56%).
- ! Over one-third have increased their focus on tobacco users (42.6%) as a result of the grant funds.

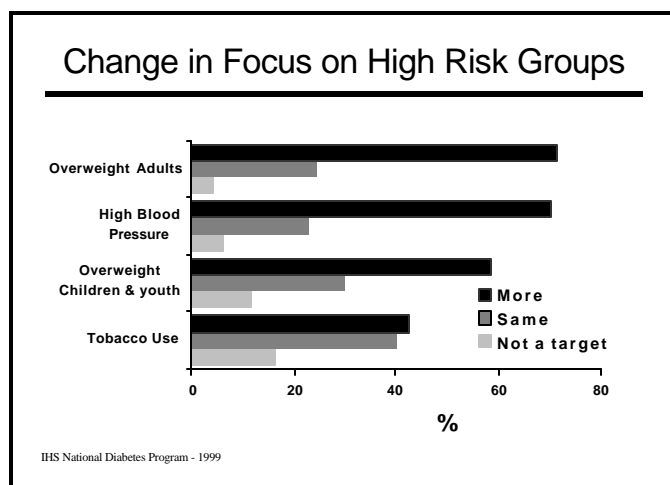


Figure 17

Target Groups for Nutrition Information

Nutrition activities target the whole community as well as people with diabetes and their families using a variety of methods (Figure 18).

- ! 32.5 percent of the programs are targeting the whole community with cooking classes, 37.2 percent offer individual nutrition sessions, and 44 percent offer group classes.
- ! More than half of the programs target family members with group classes (50.5 percent) and individual sessions (55.6 percent).
- ! Almost three-quarters of the programs (72.6 percent) use individual sessions, while about two-thirds (66.1 percent) use group classes and 43 percent use cooking classes.

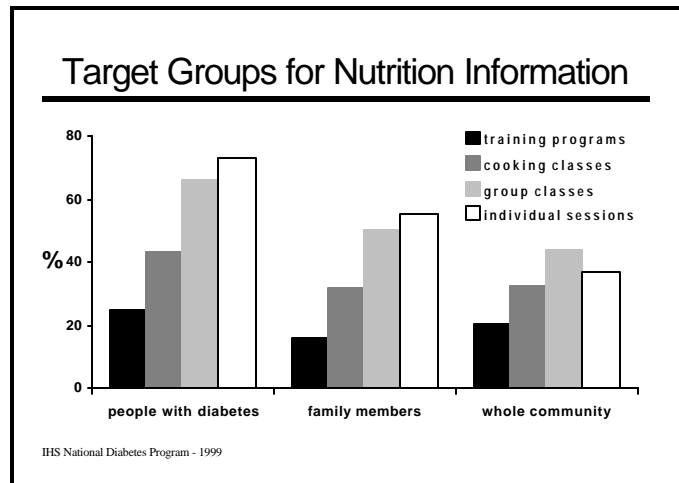


Figure 18

Increase in Nutrition Activities

Grant funds are being used to enhance existing nutrition efforts and to develop new ones directed to people with diabetes, their families, and the whole community (Figure 19).

- ! Over 60 percent of programs said they developed or enhanced individual nutrition sessions for people with diabetes.
- ! 51 percent enhanced classes for family members of people with diabetes.
- ! 45 percent were able to create new programs for family members of people with diabetes.
- ! 19% of programs improved and 10% of programs created nutrition training sessions for clinic staff.

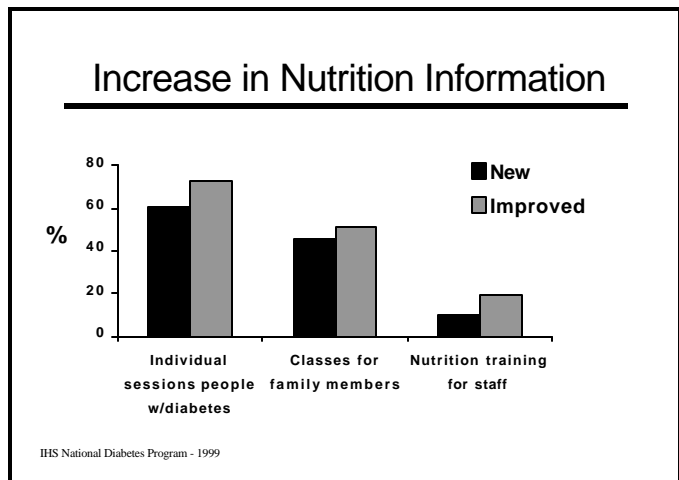


Figure 19

Use of Commodity Foods

Programs are using grant funds to enhance the Food Distribution Program on Indian Reservations (FDPIR).

- ! More than half of the grant programs (56 percent) are providing education in the healthy use of commodity foods.
- ! Over one third (36.4%) participate in the Fresh Fruits and Vegetables USDA Food Distribution Program to Indian Reservations (commodity foods).

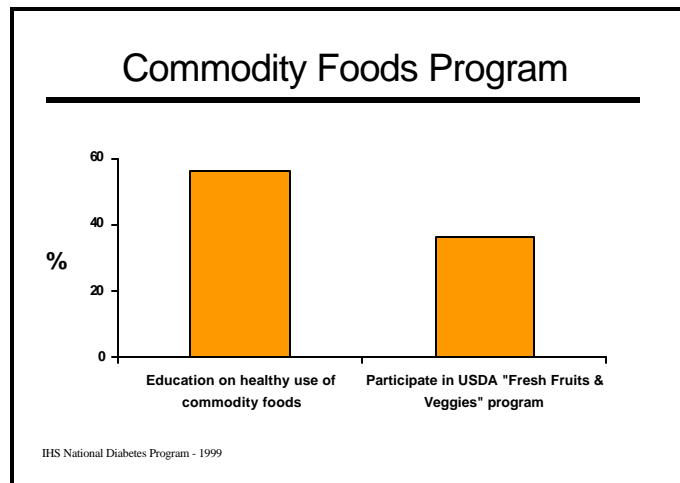


Figure 20

Target Groups for Delivering Nutrition Information to Those Who Care for Infants and Children

Programs work with other community programs for infants and children (Figure 21).

- ! About one-third or more of the programs used group classes (32.5 %) or individual sessions (37.5 %) with Head Start and Women, Infants and Children (WIC) families.
- ! More than one-third of the programs now offer group classes with Head Start/WIC families (35%) and training programs (34.7 %) for Head Start/WIC staff.

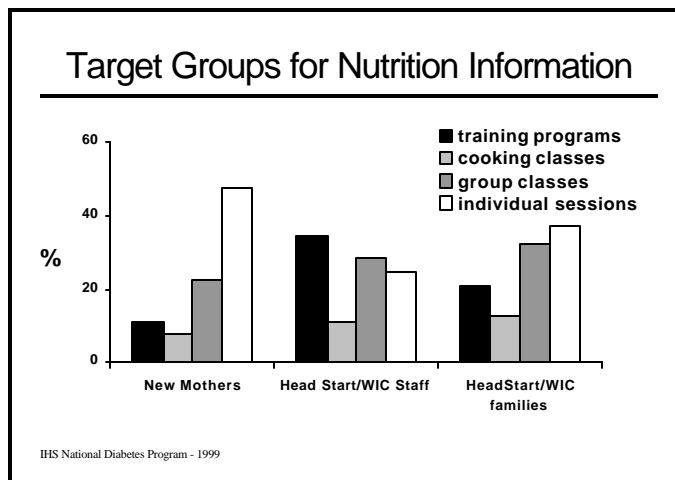


Figure 21

Program Increases in Physical Activity for Adults

Programs target the whole community for most physical activities, except team sports targeted more commonly to elementary school children and adolescents (Figure 22).

- ! About half or more of the programs target the whole community with walking clubs (52.7%) and aerobics (48%).
- ! 40 percent were doing individual consultations with the whole community.
- ! 30 percent were targeting the whole community with sports teams, traditional games and activities, and training of fitness leaders.
- ! Walking clubs and individual consultations are the most common efforts directed to elders (20% of programs or more), while almost one-quarter (23.1%) of programs are directing walking clubs to families.

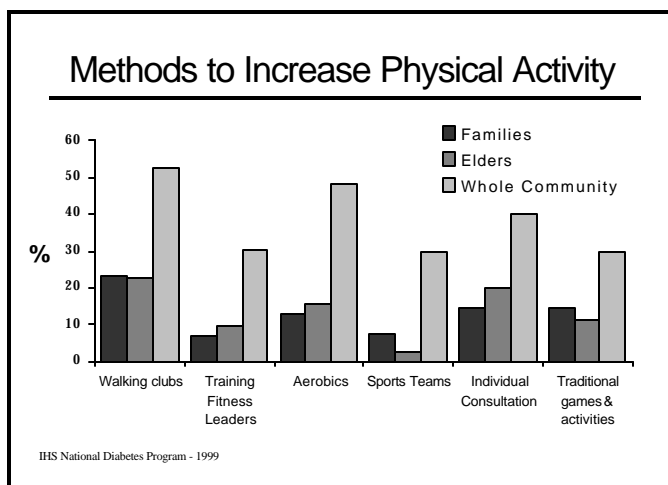


Figure 22

Increase in Physical Activity Programs for Youth

More than 30 percent of programs have increased their physical activity programs for youth (Figure 23). As a result of the grant funds, children now have access to more physical activity programs:

- ! 5% of programs offer walking clubs.
- ! 10% use traditional games.
- ! 6% offer team sports.

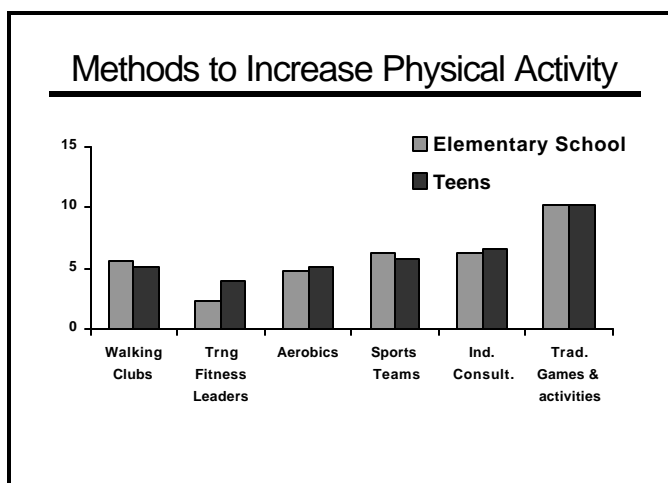


Figure 23

Diabetes Screening Activities

Programs sponsor a considerable amount of both clinic-based and community-based diabetes screening (Figure 24). Finger stick screening is more common than paper and pencil tests as a community-based screening method.

Programs to screen for diabetes target all ages, but emphasize adults primarily.

- ! About one-third (34.7%) of programs target children with clinic-based screening.
- ! About one-quarter (26%) target children with finger-stick tests.
- ! More than half and about three-quarters of programs target adults and elders with clinic-based and finger stick tests, respectively.

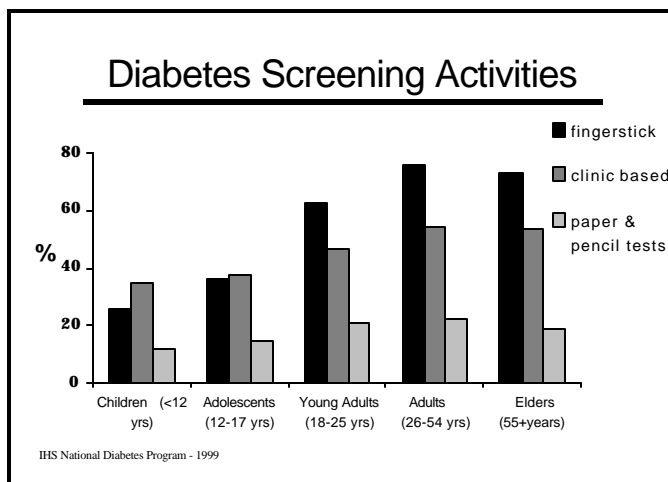


Figure 24

Screening, Referral, and Treatment for Diabetes Complications

Programs now screen, refer, and treat a variety of diabetes complications. Screening for each complication was done by at least half of all programs (Figure 25).

- ! 77.6% of programs are screening feet.
- ! 64.3% are screening for urine protein.
- ! 87% are screening for high blood pressure.
- ! Programs were most likely to refer patients for eye (80.5%), feet (76.9%) and dental care (69.7%).
- ! Programs were less likely to treat than to screen, but still more than half of the programs were providing treatment for feet (55.2%) and urine protein (52.3%), while 62.1% were providing treatment for high blood pressure.

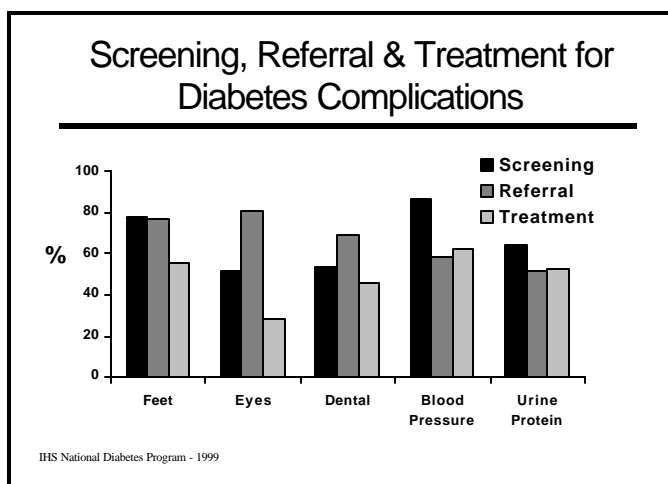


Figure 25

Education for People with Diabetes

Programs provide community-based education, education for people with diabetes, and education for health professionals with a variety of methods (Figure 26). Of the many methods for community-based education:

- ! Clinic-based 1-to-1 education was the most common method used with people with diabetes (80%).
- ! Over half of the programs provide group education and about 40% offer diabetes support groups.

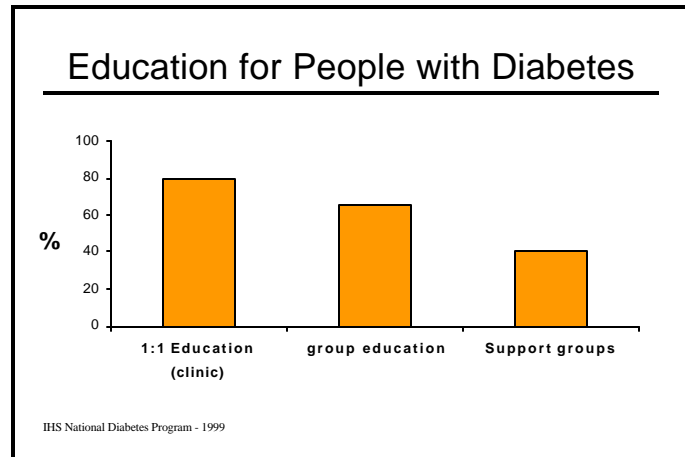


Figure 26

Community-based Diabetes Education

Programs use a variety of methods to provide patient education (Figure 27):

- ! Programs were most likely to use pamphlets (74%), newsletters (56%) and videos (38.6%).
- ! Conversely, mass media such as TV and radio were used by less than 5 percent of programs.

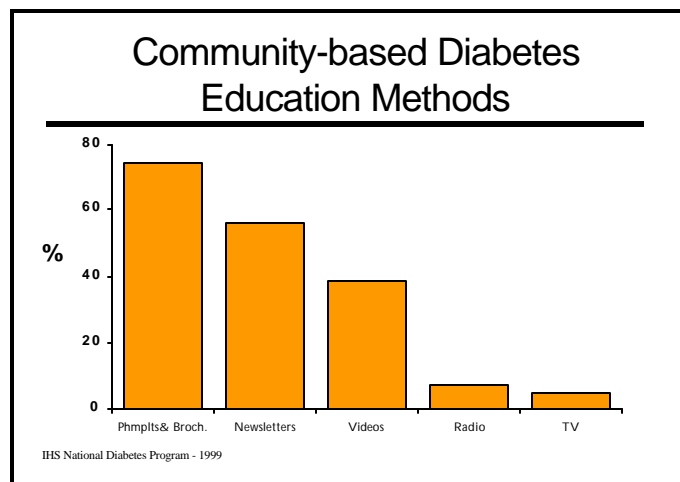


Figure 27

Community-based Diabetes Education

Community-based diabetes education is provided in different ways (Figure 28).

- ! 60% of programs use community health fairs.
- ! 23.8% provide education through community schools.
- ! 18.8 % use traditional methods.
- ! 14.8% organize diabetes camps.

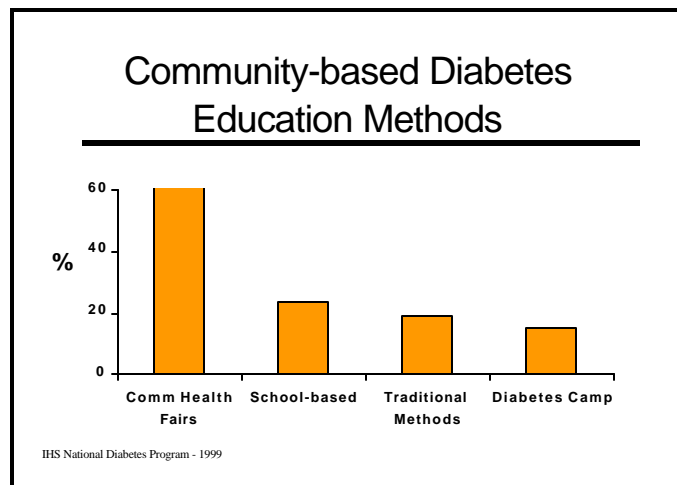


Figure 28

Health Professional Education

Several programs now emphasize increased training for health professionals (Figure 29):

- ! More than 60% offer Continuing Education (CE) programs for health care staff.
- ! About 50% offer training for CHR & Health Aides.
- ! Over 40% offer inservice training.
- ! About 30% offer Staged Diabetes Management (SDM) training.

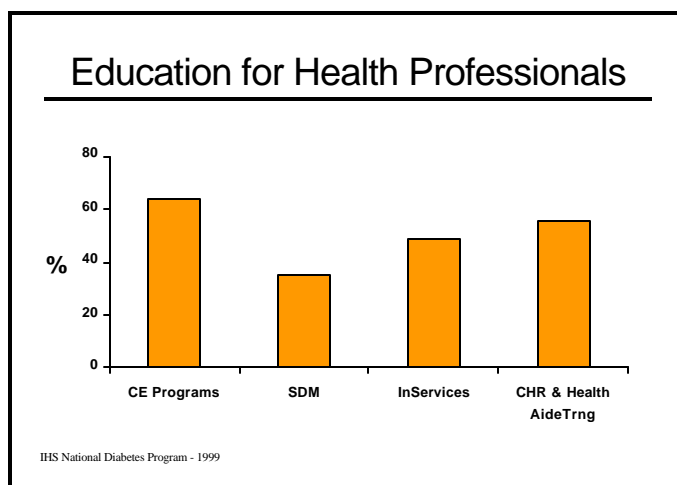


Figure 29

Traditional Approaches

A significant number of programs are using traditional approaches (Figure 30).

- ! Programs use story-telling (34.3%) and talking circles (35.4%). These culturally accepted methods allow greater sharing of diabetes knowledge within communities.
- ! 28.2% use traditional herbs or medicines in the program. Cultural healing methods help many individuals and families cope with diabetes.

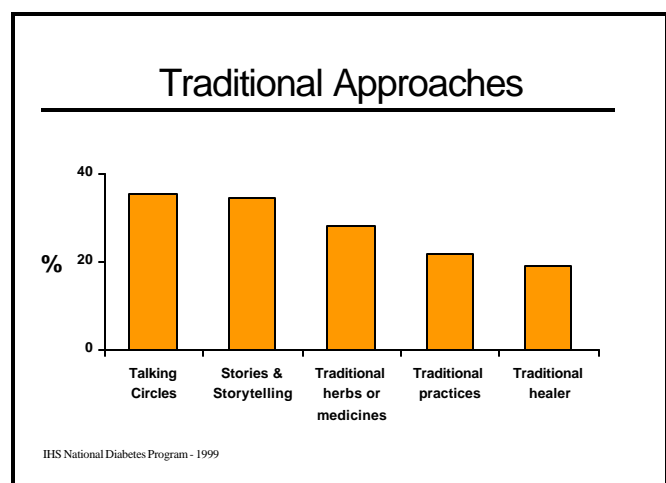


Figure 30

Developing or Enhancing a Diabetes Program

Using grant funds, programs have both enhanced existing diabetes activities and programs and developed new ones (Figure 31).

- ! 29% established a new diabetes team; 42% improved an existing team.
- ! 42% of programs created new diabetes registries; 48% improved existing registries.
- ! 21% of programs established new diabetes clinics; 43% improved an existing clinic.

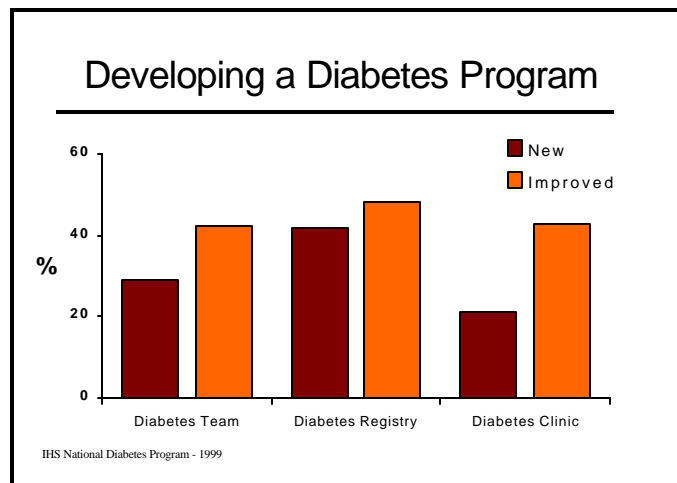


Figure 31

Improved Clinical Management Practices

Programs have improved their clinical management practices (Figure 32). Half of all programs report improvement in clinical management practices as a result of receiving the grant funds.

- ! 49% of programs now report using a diabetes flowsheet.
- ! 56% of programs that did not participate before are now participating in the *Diabetes Care and Outcomes Audit*.

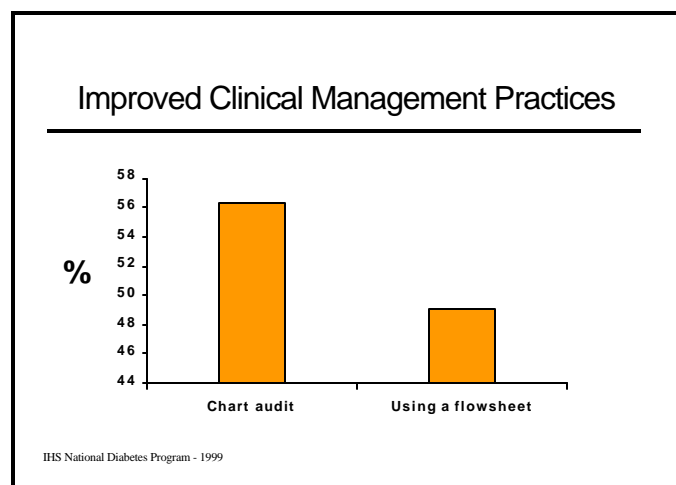


Figure 32

Change in Program Activities as a Result of the Grant Funds

Programs report doing more diabetes program activities (Figure 33):

- ! 86.6% of programs report that since receiving the grant funds they are doing more planning.
- ! 73.3% of programs report that they have improved their diabetes data systems.
- ! About 60% report more administrative support for diabetes activities.

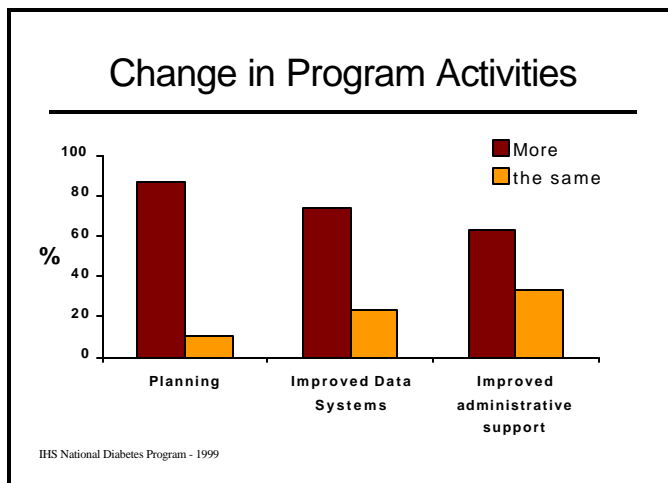


Figure 33

Change in Program Activities as a Result of Grant Funds

Using grant funds, programs are increasing diabetes screening, education and clinical services (Figure 34):

- ! 87.4% of programs say that since receiving the grant funds they are providing more diabetes education.
- ! 74.7% say they are doing more diabetes screening and nutrition activities.
- ! Programs reported the lowest percentage of grant activity in clinical services and physical activity. Yet, almost 60 percent of grantees report that they are doing more—58.8% and 58.1%, respectively.

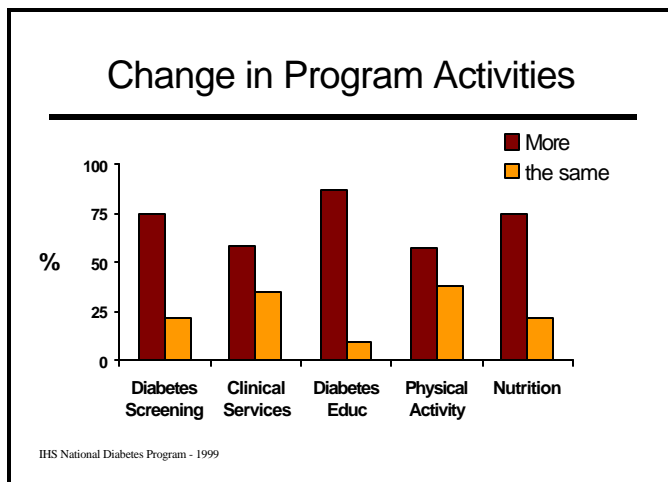


Figure 34

Program Barriers

Fifty percent of programs listed no major barriers to implementing their programs. Half of the programs cited particular barriers (Figure 35) including:

- ! Building space is cited as a barrier to 44% of programs.
- ! Hiring new staff (45.5 %) is the next most common barrier.
- ! Staff turnover and delays in the grant planning phase are both cited as a barrier by about one-quarter of grantees.

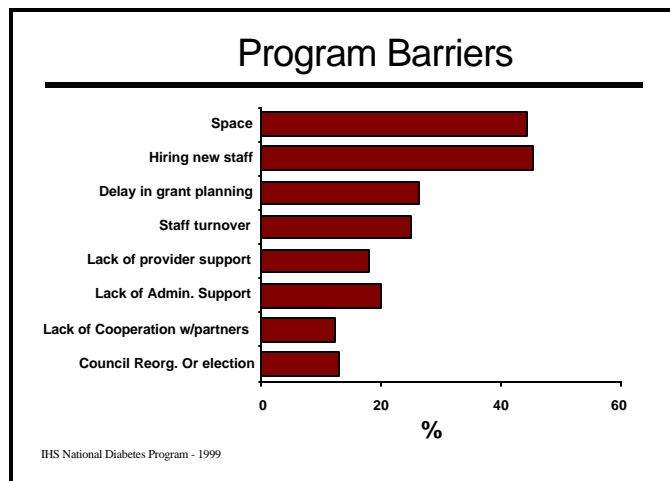


Figure 35

New Providers Added to the System

Grant funds have been used to enhance the staff of most programs (Figure 36). Almost one-half or more indicate that because of the grant funds they have included:

- ! Program coordinators (61.7 %).
- ! Diabetes educators (50.9 %).
- ! Registered Dietitians (RD)/nutritionists (49.5%).
- ! Nursing position (42.9 %).
- ! Almost one-third or more have provided medical specialists (36.8 %) or physical activity specialists (32.1 %) because of the grant funds.

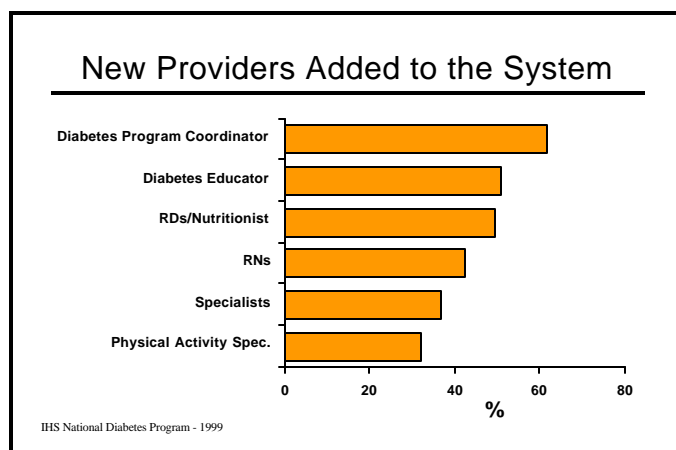


Figure 36

Unfilled Staffing Needs

Grant Programs have trouble filling key positions (Figure 37):

- ! The most common unfilled staffing needs of programs are physical activity specialists (51.3 percent) and diabetes educators (43.3 percent).
- ! About one-third or more of the programs have trouble filling positions for RDs/nutritionists (33.2 percent) and medical specialists (30.7 percent).

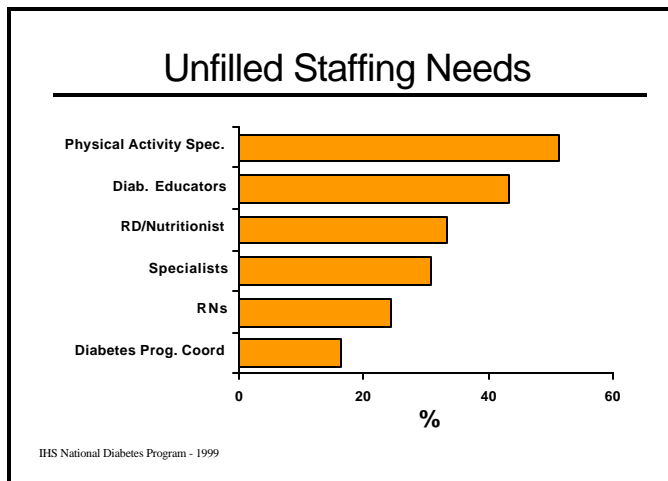


Figure 37

Technical Assistance Needed from the IHS Diabetes Program

Figure 38 shows technical assistance needs within the diabetes grant programs. The IHS National Diabetes Program is using the Area Diabetes Consultants, Model Diabetes Programs, Tribal Epidemiology Centers and other partners as resources to provide technical assistance within each IHS region. The most common technical assistance needs include (Figure 38):

- ! More than half of the programs (55.9 percent) need assistance with statistics and data analysis.
- ! More than 40 percent of programs cited a need for assistance with planning and community assessment (40.3 percent), and epidemiology and surveillance (46.9 percent).
- ! The need for technical assistance in clinical treatment and guidelines was less needed but was suggested by more than 20 percent of programs.

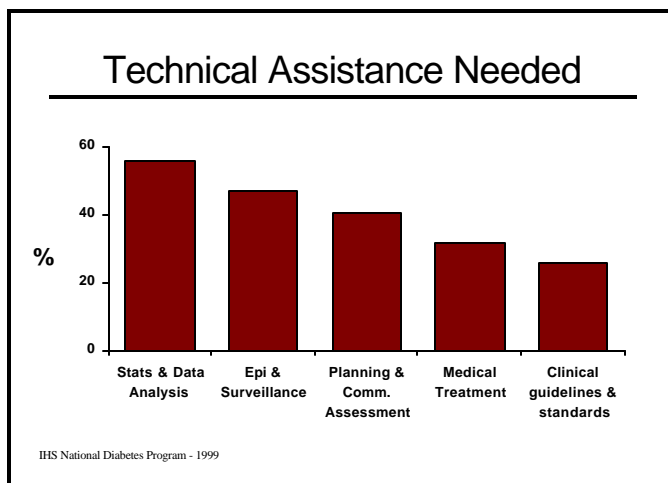


Figure 38

General Technical Assistance Needed

Types of technical assistance needed (Figure 39):

- ! Helping clients change behavior is the most commonly cited technical assistance need of programs. Almost three-quarters of the programs (72.9 percent) say that they have this need.
- ! Sites also indicated a need for technical assistance in computerized RPMS/PCC training (47.6 percent), developing diabetes educational materials and grant writing (both 43.7 percent), and conducting the diabetes chart audit and using Epi Info software (41.9 percent).

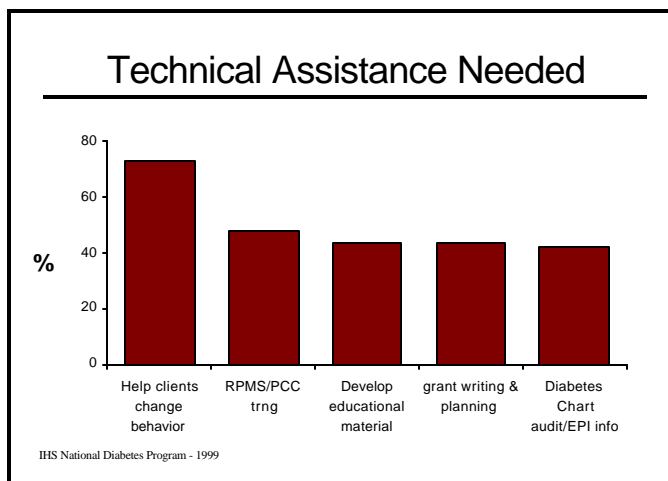


Figure 39

Technical Assistance in Evaluation

Most programs indicate a significant need for technical assistance in evaluation (Figure 40).

- ! More than 60 percent of programs need assistance with measuring their system's improvement (62.4 percent) and with using statistical and data analysis in evaluation (60.7 percent).
- ! Technical assistance needs for about one-half or more of the programs include: basic evaluation training, defining and measuring outcomes, identifying outcomes other than laboratory outcomes, and determining if efforts have been effective.

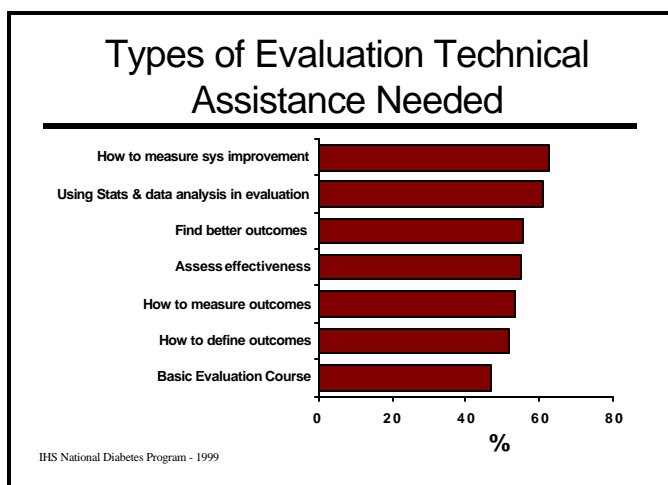


Figure 40

Conclusion, Discussion, and Recommendations

Recipients of the *Special Diabetes Program for Indians* grants have made an ambitious start in these first two years down the long road to diabetes prevention in tribal communities.

- ! Activities developed under the grants target all ages and a spectrum of groups at high risk for diabetes itself and for complications.
- ! Efforts to increase physical activity and to improve nutrition extend to all age groups from children to the elderly, and coordinate with other community resources when there is an opportunity.
- ! Diabetes education programs have been created or enhanced for all patients and their families in AI/AN communities where a significant number of the adults have already been diagnosed with diabetes.
- ! These activities include not only case identification through blood sugar screening but efforts to identify people with diabetes at risk for complications at an early and treatable stage.
- ! Grantees have adopted proven systems changes to enhance clinical management and have begun training their health care professionals to bring the latest clinical science into clinical practice on the reservation.

Significant challenges remain. Staff positions are difficult to fill in some locations and space is often limited. New and better medications to treat diabetes are released almost monthly but are priced beyond the reach of many programs. Most importantly, community prevention activities are by nature long term and the pay off is not always obvious. Nevertheless, the epidemic of diabetes and its related complications is too severe for tribes to wait until all the important controlled research studies are final. The grant program has given the initiative to individual AI/AN communities, and their response has been overwhelming.

In summary, the challenge is great and these funds have enabled American Indian and Alaska Native communities to move substantially further down the path to healthy lifestyles and comprehensive diabetes care. Diabetes prevention on all levels should bring the health of this population to the same level as that of all Americans in the next millennium. With these grants, American Indian and Alaska Native communities are finding their own paths

Data Improvement Fund Distribution

Based on concerns by tribal leaders that diabetes prevalence and mortality data were inaccurate or incomplete, the IHS Director set aside funding to improve diabetes-related data within each Area. The formula for allocation of funds for the *Special Diabetes Program for Indians* included a set aside of 5 percent for the improvement of diabetes-related data collection, analysis, and reporting. The funds, in the amount of \$116,000, were distributed to each IHS Area and to the IHS National Diabetes Program. The same funding amount was available for Year 1 and Year 2 of the grant program. These funds were reduced to approximately \$82,000 in Year 3 to compensate for a correction in the distribution to the California Area (Appendix B).

These data improvement funds have enabled each IHS Area to address the need to verify, validate, and refine diabetes prevalence, complications, surveillance, and mortality data. This activity to ensure accuracy as well as uniformity in reporting of the data is essential to allow comparison of data within each IHS Area and between IHS Areas. These funds have also allowed IHS, in partnership with the National Indian Council on Aging (NICOA), to begin to use GIS technology to “map” the problem of diabetes in AI/AN communities¹³

In addition, the funds have also provided an opportunity for NICOA, tribally operated regional epidemiology centers, and others familiar with the IHS Registered Patient Management System (RPMS) to refine the RPMS capabilities. NICOA is working with IHS, tribal and urban health clinics to develop an automated diabetes outcome and audit measures report using the RPMS.

These data improvement funds have allowed IHS Areas to:

- ! Improve and update patient registries and patient care record systems
- ! Develop new systems to extract data for reporting requirements
- ! Examine the accuracy of diabetes data
- ! Provide training in patient care registry systems, data use, *Diabetes Care and Outcomes Audit*, and other epidemiology related activities

An important outcome to note is that these data improvement funds have enhanced tribal participation in the *Diabetes Care and Outcomes Audit*, enabling tribes to ascertain diabetes care at the local level and compare it to other programs in the region and throughout the Indian health system. In addition, the data improvement funds have allowed local staff to identify tribal resources, to find personnel skilled at data systems and analysis, and to expand opportunities to provide training and technical assistance to other tribes.

Program Surveillance Activities

Preventive Services

Comprehensive preventive services for individuals with diabetes are expensive. Managed care plans in the U.S. are very concerned with developing effective disease management programs. In 1992, it was estimated that 4.5% of the total U.S. population had diabetes, but these individuals accounted for 14.6% of the total U.S. health care expenditures.¹⁴ In 1997, the American Diabetes Association estimated that inpatient, outpatient, and drug costs for people with diabetes averaged \$10,071 per person with diabetes compared to \$2669 per person without diabetes.¹⁵

Yet, yearly per capita distribution to the IHS is \$1,575. ***Comprehensive preventive services are simply beyond the economic reach of most Indian health facilities.*** As new and effective diabetes medications are introduced in the U.S., they typically become available in AI/AN communities only after several years when the prices fall. ***The consequences of the delay are costly.***



There should not be any reason why our people are only getting 30%-40% of healthcare (dollars) as compared to the rest of the country...I hope that whatever direction we take, that you would always remember those who are going without...who are afflicted with this disease."

**Alvin Windy Boy Sr, Chippewa Cree Tribe, Councilman,
Chairman, Tribal Leaders Diabetes Committee**

Data from managed care plans show the dilemma. Kaiser Permanente estimates that per person costs for individuals with diabetes increased 50% after the initiation of cardiovascular drug therapy, but the costs increased 360% after a major cardiovascular event. Abnormal kidney function increased diabetes treatment costs by 65%, but with end-stage kidney disease the costs rose by 771%. Health care systems often think they cannot afford the increased costs of preventive therapies. Yet, they will face even greater costs when complications ensue. In the year 2000, tribes will be unable to afford comprehensive preventive services in the short term, but this will lead them into a profound dilemma. They cannot afford ***not*** to provide the services for the sake of the longer term.

Managed care plans have worked hard to develop and evaluate disease management programs to curtail the morbidity and subsequent costs of diabetes. ***Medical Practice guidelines and quality***

standards have been proposed by a number of organizations. Studies show the cost-effectiveness and efficacy of case management. The Indian health care system has used these same strategies of managed care, but for a longer period of time. The IHS National Diabetes Program pioneered the effort to define standards of care for people with diabetes based on current research and to measure the implementation of these standards through the *IHS Diabetes Care and Outcomes Audit*.

In the late 1980s, the methods for conducting the audit were piloted in several programs. By 1992 the care of more than 40,000 individuals with diabetes was reflected in the overall assessment. The number of charts audited from 1992 to 1998 increased from 6,959 to 11,581 (Figure 41). As tribes have assumed administration of their health services under self-determination, and have participated in the diabetes grant program, more and more small tribes have joined in the process to measure and improve care.

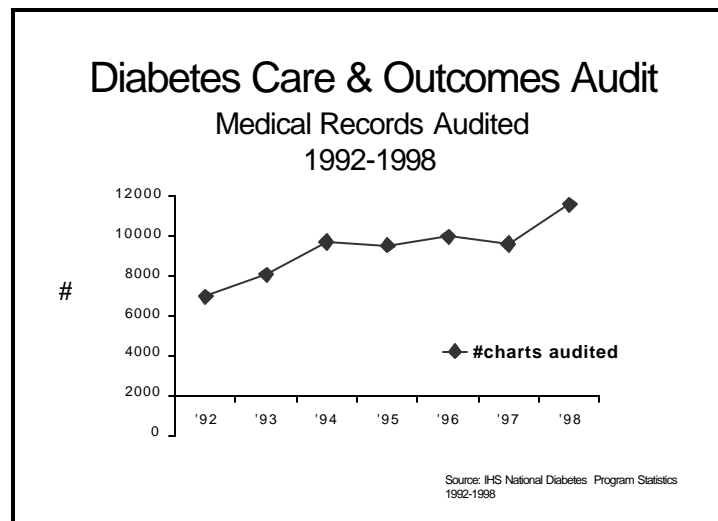


Figure 41

Thus, when the Health Plan Employer Data and Information Set (HEDIS) measures called for programs to provide the rate of dilated eye exams in people with diabetes, Indian health facilities could easily measure their trends (Figure 42).

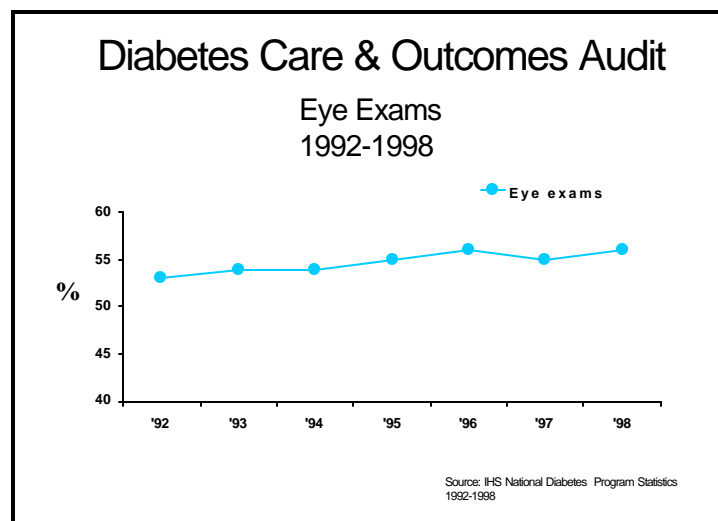


Figure 42

People with diabetes die from pneumonia and influenza at higher rates than people without diabetes. Indian health facilities, with few dollars available, made sure that cost-effective, preventive strategies such as immunizations were implemented (Figure 43).

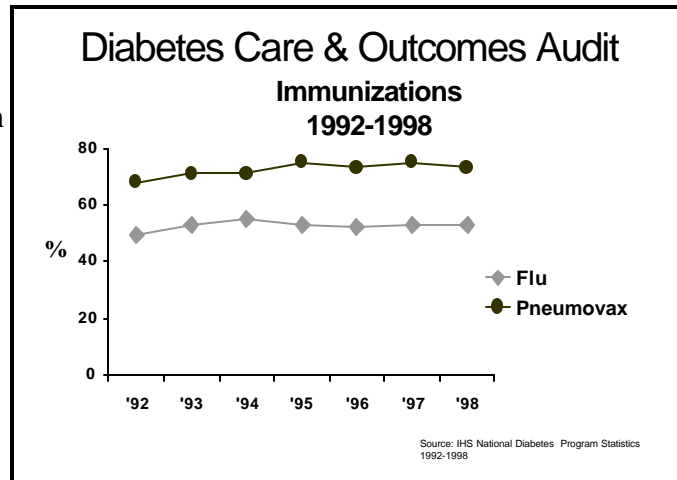


Figure 43

Diabetes self management education was measured and tracked as facilities were able to develop programs under severe budgetary restraints (Figure 44). As the costs of care increased in the 1990's, Indian health facilities have continued to track diabetes care and develop diabetes prevention strategies. The economic consequences of diabetes are frightening for self-determination contracts where tribes assume the responsibility for health care expenditures. ***When nearly 5% of the population in the U.S. accounts for 14% of the health care expenditures, how can tribes with almost half their adult population already diagnosed with diabetes afford comprehensive care and community***

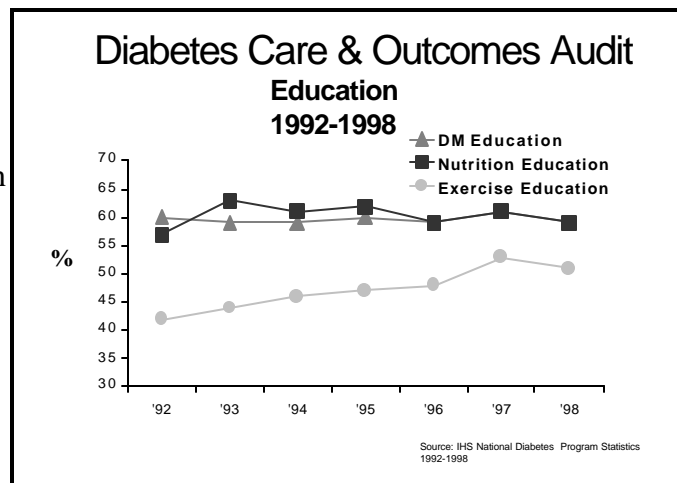


Figure 44

prevention? Yet, if prevention programs are not supported, the costs in terms of morbidity, mortality, and health care expenditures will only increase.



I remember when, in 1985, I was working in South Carolina, a fasting sugar of 200 was considered good enough and that's just shocking today . . . I don't think we realized how important tight blood sugar control was . . . these things are much clearer now . . . and help us give better guidance to patients about issues really important to them.

Jane Kelly, MD, Alaska Area Diabetes Consultant



The other day I told my doctor that I quit taking that medicine, the diabetes medicine. I never did know what it was doing. I didn't get sick, I didn't feel bad or anything, so I quit. . . I didn't take any for about 12 days.

I got an appointment to the doctor. They checked my blood. It was real bad. I didn't take that medicine to see what would happen. Well then I saw what would happen. So then I knew what it was for. For four years I didn't know why I was taking the pill except that they said I was a diabetic and that was a pill for diabetes. That's all I knew.

Vern Antone, Kiowa

Cardiovascular Disease

Cardiovascular disease was once considered rare in American Indians, but the increasing rates of diabetes have brought an “epidemic” of heart disease along with the diabetes epidemic.¹⁶

Cardiovascular disease death rates for Indians are now higher than comparable rates for the U.S. Caucasian population.¹



Apparently, I had been diabetic for quite some time and did not know it. And it had already damaged my heart.

Dean McManus, Chickasaw, diagnosed with diabetes in July 1995

These striking figures are a marked change from the situation 20 to 30 years ago when a heart attack was unusual in most of the Indian population. This rise in coronary heart disease is attributable in large part to increasing rates of diabetes. American Indian women who have diabetes are 4 times more likely to have a heart attack than American Indian women who do not have diabetes. For American Indian men with diabetes the risk is twice as high. In addition, individuals with diabetes who have heart attacks are more likely to die from the heart attack than individuals without diabetes.² The extensive and successful public health efforts to reduce coronary heart disease rates in America have largely bypassed AI/AN communities.

Most Indian health diabetes programs struggle to provide preventive foot care, blood sugar control, hypertension control, eye exams, and all the many services needed to maintain the health of individuals with diabetes. Every year more studies are released showing the benefit of new medications and lifestyle interventions. Most people with diabetes require 7-10 medications in addition to lifestyle interventions to manage their disease.¹⁸ Indian health facilities are struggling to implement these preventive approaches.



The way we understand is diabetes usually attacks the eyes and feet first . . . Make sure the doctor sees your feet, you know, and your toes before you leave the clinic.

Catherine Quintana, Elder, Pueblo of San Felipe, 67 years old

Publication of the results from the Strong Heart Study of cardiovascular disease in American Indian communities now show the very close relationship between diabetes and cardiovascular disease. In the past several years, other landmark cardiovascular disease studies have also been published.^{19, 20} These studies show that individuals with diabetes and coronary heart disease benefit from lipid lowering therapy as much or more than individuals without diabetes. Guidelines for primary and secondary prevention of coronary heart disease in people with diabetes have been revised to reflect these studies.²¹

Many Indian communities are unaware of the close association of diabetes and heart disease and the changing recommendations. Diabetes is thought of in terms of amputation and dialysis, but today heart attacks are actually among the most common complications of diabetes in Indian communities.



The thing that we are trying to overcome, is that . . . if they get diabetes, that it's a death sentence or they're really complacent about it. My grandparents had this, they got their legs cut off, they lost their eyesight, so this is what in store for me.

Diane LaFontaine, Diabetes Coordinator, Quentin Burdick Memorial Health Care Facility, 1,060 patients on diabetes

The lifestyle opportunities for preventing heart disease are similar to interventions for preventing diabetes. The whole public health impact of heart disease and diabetes is only now being addressed in a preliminary way.²² Yet, prevention opportunities abound.

AI/AN communities are in a health crisis. In only 25 years, coronary heart disease has gone from extraordinarily rare to unremarkably common in many Indian communities.²⁵

As the U.S. has made progress in combating heart disease and stroke, there has been a growing recognition that increasing diabetes rates threaten to dampen the progress in reducing heart disease mortality in this country.²³ Indian smoking rates are very high in the Northern and Central plains as well as other regions of the U.S., aggravating the risks for heart disease and stroke in the increasing numbers of individuals with diabetes and without diabetes.²⁴ The Indian health system is now faced with the need to integrate all aspects of coronary heart disease prevention into diabetes care for the growing number of individuals with diabetes.

Indian health providers have been measuring cardiac risk factors in the course of their diabetes care and outcomes audit. Levels of blood fats are measured often (Figure 45). In 1998, 79% of patients with diabetes had their cholesterol measured. Of those, 35% had a cholesterol of 200 or greater, which is of concern.

The new recommendations from the American Heart Association specify that not only does total cholesterol need to be measured, but a whole lipid panel including LDL cholesterol has become very important.²⁴ In 1998, only 29% of Indian patients with diabetes had this more expansive total lipid profile completed and over half of those tested did not have levels of LDL at 100 or less (Figure 45).

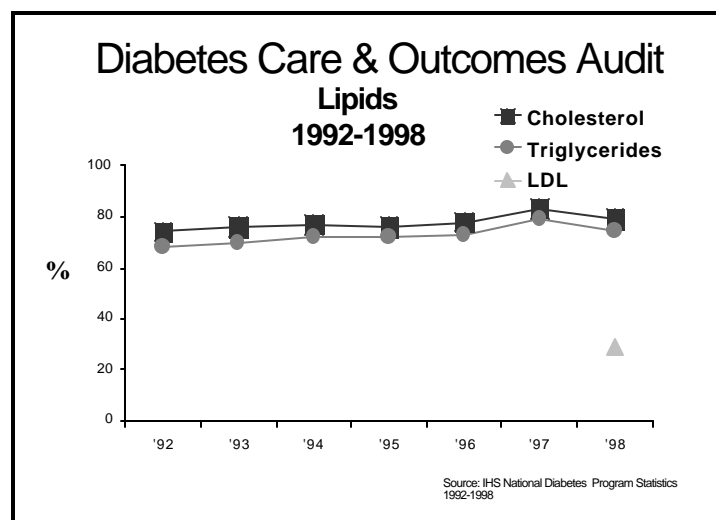


Figure 45

Because all individuals with diabetes, even those without symptoms, are likely to have heart disease, these new targets for blood lipids have been recommended. To achieve these levels, many patients need drug therapy with the newer medications to reduce cholesterol and more expansive lipid monitoring. These advances are a continuing challenge to the system, but the prevention of heart disease in diabetes holds an enormous potential benefit for this disadvantaged population.

Hypertension is also an important cardiovascular risk factor. Indian health facilities have monitored trends in blood pressure with the diabetes care and outcomes audit (Figure 46). The United Kingdom Prospective Diabetes Study (UKPDS) showed the importance of hypertension control in diabetes. Lowering the average blood pressure from 154/87 to 144/82 decreased diabetes deaths by 32%. In 1998, 61% of patients treated in Indian health facilities participating in the audit

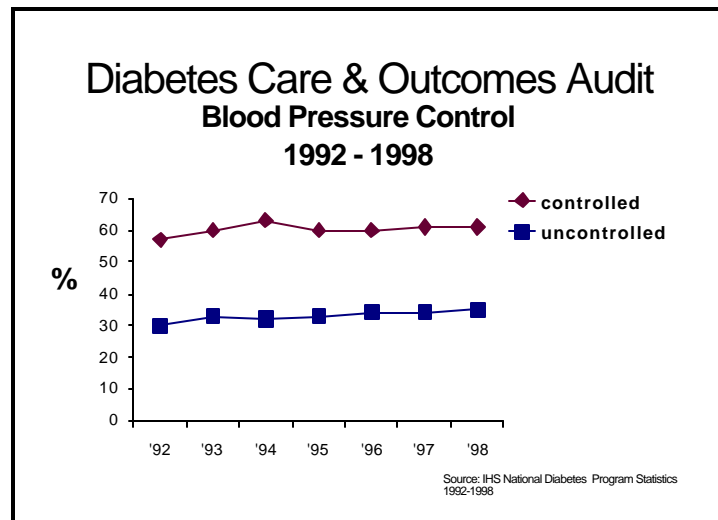


Figure 46



If I had it to do all over again, I would follow a path of healthier living. I would have watched my diet and took my medication when I was supposed to. I think that's the path I would have followed . . . My condition now prevents me from walking through the forest, the woods. I used to like to hunt and I can't do that anymore. . . I used to swim in the lake . . . I used to like to play sports . . . Now, I am restricted to this chair . . . That was the hardest part of being a diabetic . . . was losing my limbs. And if I would give advice to anybody, if they know they got diabetes, take care of it , get educated on what it could do to you.

Lawrence Bedeau, Red Lake Band of Chippewa, 55 years old,

health care providers can continue to adapt their treatment goals to the latest targets. The data show the success of these efforts in reducing blood pressure.

One of the most important cardiac risk factors is smoking. The recent report from the Surgeon General on Tobacco Use Among U.S. Racial / Ethnic Minority Groups shows that the rates of smoking vary widely in AI/AN communities with Northern Plains Indians having up to 44% of adults who report that they currently smoke. Indian health providers have collected data on tobacco as part of the diabetes care and outcomes audit (Figure 47). There are marked variations between regions in recording and counseling about tobacco. Smoking cessation is very important for individuals with diabetes to decrease cardiac risk, peripheral vascular disease, and deterioration of renal function.

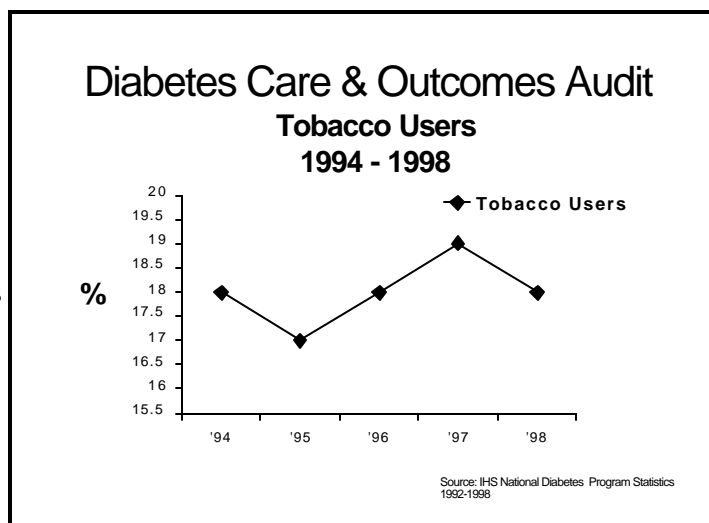


Figure 47

Amputations

Of the many complications of diabetes, lower extremity amputation is the one most visible in Indian communities. Individuals who have lost both legs to diabetes appear in wheel chairs at community functions and many houses have ramps to accommodate them. Amputations are dreaded and devastating, not only because of the loss of mobility, but also because they appear to happen without warning and often in association with other problems like kidney failure.

Many amputations are avoidable, but it takes resources, training, and special care and education.²⁵ Risk factors for amputation described in the Pima Indians include nerve problems, vascular



When we were growing up back in the 50s . . . you didn't see the wheel chairs that you do nowadays. People didn't have diabetes and it was our own diet that kept it away.

Lawrence Bedeau, Red Lank Band of Chippewa, 55 years old, diagnosed with diabetes in 1974

disease, and long duration of diabetes.²⁶ When individuals with diabetes have high blood sugars for long periods of time, they can lose the ability to feel small injuries and to “protect” their feet normally. However, they are usually totally unaware of this and sometimes only know about problems when there is a serious ulcer and infection. In addition, vascular disease that is also common in individuals with diabetes makes it hard for sores and ulcers to heal, especially if the individual continues to walk with unrecognized foot problems.

Primary care providers and their tribal health department in Northern Minnesota know how to reduce amputations:²⁷

- ! The first element of their program is to screen all people with diabetes to find those who have lost “protective sensation” or who have other risk factors such as a history of a previous foot ulcer or amputation. These people need special attention to footwear and, in some cases, they need special shoes. They also need regular foot care to prevent injuries and to reinforce self-care.
- ! The second element of the program is to have clearly defined protocols for dealing with foot ulcers, including whom to hospitalize and refer off reservation for specialty care and revascularization surgery.
- ! The third element is a follow-up wound-healing clinic to provide the expert care and follow-up necessary to heal the chronic ulcers.

When all these elements were incorporated into the program, the amputation rates dropped from 29 per 1000 patient years to 9 per thousand patient years.³⁰

The *IHS Diabetes Care and Outcomes Audit* also measures comprehensive foot exams because of the importance of assessing for amputation risk and providing follow-up based on risk profiles. The percentage of foot exams performed has steadily increased from 1992-1998 (Figure 48). The change from a simple visual foot check to a comprehensive foot exam occurred in 1993.

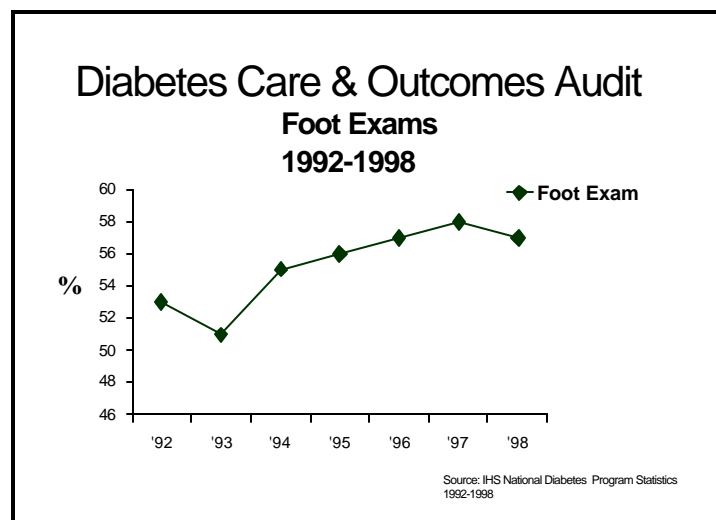


Figure 48



With the special grant money . . . the tribe and us, in partnership, have expanded the diabetic shoe program which will make it easier to prevent foot ulcer in people with neuropathy.

**Ray Grandbois, Turtle Mountain Band of Chippewa, Service Unit
Director for Quentin Burdick Memorial Health Care Facility**

Getting foot care programs to the scattered and remote reservation communities in the U.S. is particularly important for dialysis patients with diabetes. In an analysis of the Medicare data on End Stage Renal Disease from 1991-1994, American Indians on dialysis were 28% more likely to have an amputation than were Caucasians.²⁸ American Indians suffered amputations at the rate of more than 16 per 100 in a year.

For these individuals, prevention and regular foot care are crucial, but it may not happen where resources and expertise are limited. Building successful programs is a challenge. Outreach to dialysis facilities, on reservation and off reservation, requires teamwork and expertise. A selected number of American Indian communities have developed the process, but the opportunity to extend preventive foot care to all is urgent and compelling.

Dialysis

Dialysis is ever present in the lives of many Indian families.²⁹ In the mid 1970s and early 1980s when a person needed dialysis from diabetes-related kidney disease, he or she was transferred to a city for treatment. Often the family had to move or the patient endured long hours of transportation to and from treatment facilities. Tribes then developed their own dialysis units on the reservation. These units were not part of the IHS hospital or clinic. As the number of people needing treatment grew, dialysis units began to appear even in small and remote reservation communities.



We have a state of the art dialysis unit here, but because we needed it right away, we gave up a 17-bed pediatric wing at this hospital. And that's gone . . . forever. We'll never get it back. But in place of it, we have a state of the art dialysis unit and we're making use of it. But that's just one example of us having to give up a lot of things.

John Eagle Shield, Standing Rock Sioux, CHR Director, Ft. Yates

The magnitude of the dialysis challenge is staggering. A recent story in the Arizona Republic reported that Pima Indians suffer from kidney failure at over 20 times the rate of the U.S. general population, and over 90% of the cases are caused by diabetes.³⁰ The newspaper article called the facility “diabetics’ death row,” a place where 100 individuals are currently on dialysis. The Pima Indians are but one of many Indian communities with high rates of diabetes-related kidney failure.

Physicians and nurses now know that kidney function can be preserved with proper treatment, including blood pressure control, blood sugar control and treatment with specific medications such as ACE inhibitors at the earliest sign of kidney disease.³¹ Research has continued throughout the 1990s showing how to preserve kidney function. Indian health facilities have assessed the extent to which these strategies have been implemented with a special report on Renal Preservation that was incorporated into the comprehensive *IHS Diabetes Care and Outcomes Audit*.

Figure 49 shows the ongoing translation into practice of diabetes kidney research on testing and treatment for kidney disease in AI/AN communities. When the ability to measure microalbuminuria became widely available in 1995, Indian health facilities incorporated the test in their monitoring for those whose regular urine test did not show protein. In 1996, Indian health providers began to measure the percentage of people with diabetes treated with these important medications, as the importance of using ACE inhibitors was emphasized in diabetes research studies.

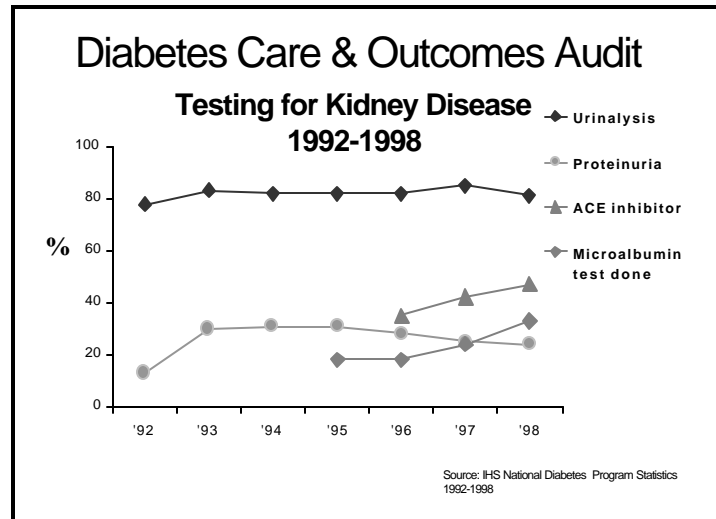


Figure 49

Preliminary trends from the U.S. Renal Diabetes Surveillance (USRDS) data show that these efforts to prevent kidney failure may be making an impact (Figure 50).

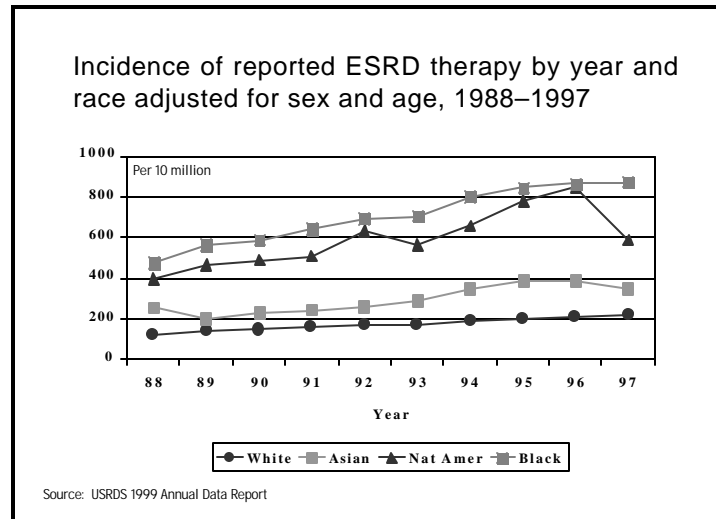


Figure 50

Science shows that dialysis does not have to be the inevitable consequence of diabetes. But implementing important research findings in Indian health care settings with limited pharmacy budgets, minimal training, and overcrowded clinics is difficult. Community health workers are overwhelmed with the needs of current dialysis patients and have no time left for efforts to prevent kidney failure among others with diabetes living in the community.

Despite the advances in science, dialysis remains the end of the line for diabetes treatment in many Indian communities. Opening a dialysis unit on the reservation is greeted with mixed feelings. The large numbers of American Indians on dialysis need treatment near home. But the dialysis unit has become a very tangible sign of the devastating epidemic of diabetes that continues to afflict Indian communities.



We just opened our dialysis center, and I'm sad that we built it. I'm sad that we couldn't spend that \$1 million for prevention.

Joyce Dugan, former Principal Chief, Eastern Band of Cherokee Indians

Diabetes and Pregnancy

At the beginning of this century, women with diabetes could not expect to deliver a baby. Today women with diabetes deliver healthy babies, but it takes sophisticated medical care, modern technology, and hard work by the mother.

Before and During Pregnancy

AI/AN women in the childbearing years have to be concerned about diabetes. Because type 2 diabetes, the predominant type of diabetes in AI/AN communities, can occur at a young age, Indian women may have unrecognized diabetes when they conceive. Poorly controlled diabetes in the early stages of pregnancy can cause serious congenital malformations.³² In addition, AI/AN women may develop gestational diabetes during the pregnancy. ***For these reasons, Indian Health Service recommends special screening for diabetes both early in a pregnancy and later.***

Even if everything is normal early in the pregnancy, a repeat screen for gestational diabetes is recommended. If the screening is positive, more lab tests are needed to confirm the diagnosis of gestational diabetes. Gestational diabetes is simply diabetes first recognized during pregnancy. Once gestational diabetes is recognized, a mother needs to monitor her blood sugar up to six times a day, eat wisely, and give herself insulin shots if needed. Unfortunately, close follow-up to make sure the fetus is developing normally is not always available on the reservation.

Rates of Gestational Diabetes

Published figures show that 13.5 % of deliveries among Indian women in the Zuni Pueblo occurred among women with diabetes, a much higher rate than the 2-3% seen in the U.S. general population.³³ Even in Alaska where the rates of diabetes are relatively low, over 6% of the deliveries occurred among women with gestational diabetes.³⁴

After Pregnancy: The Mother's Risk

In a diabetic pregnancy, the challenges are not over, even after the delivery, . Further testing has to occur at least 6 weeks after delivery to see if the diabetes has resolved after the pregnancy. Usually the glucose tolerance is normal after delivery, but the young woman is still at very high risk of developing type 2 diabetes within a few years. Gestational diabetes has been described as the “herald” of diabetes. On the Navajo reservation, projections showed that 70% of women with gestational diabetes could expect to develop type 2 diabetes within 11 years.³⁵ Similar high rates were documented in the Zuni Pueblo, where 30% of women with a history of gestational diabetes developed diabetes within 5 years of the pregnancy.³⁶

The Diabetes Prevention Program, a multi-center study of diabetes prevention in the U. S. sponsored by NIH, includes Indian women with a history of gestational diabetes. This important research will compare lifestyle changes and medications to find the most effective way to prevent diabetes in these young women at high risk for developing diabetes. When the studies are completed, Indian communities will need the resources to translate the research findings into everyday practice.

Meanwhile, many tribes are trying to help young women with a history of gestational diabetes make healthy lifestyle changes to decrease their risk of diabetes. These changes, including increased physical activity and exercise as well as healthy eating, are very important for the whole family.

After Pregnancy: The Child's Risk

The unique Pima studies of the long-term consequences of diabetes in pregnancy show that children born of a diabetic pregnancy are likely to become overweight at a young age and develop diabetes in their teen years or the early 20s.³⁶ In addition, when they develop diabetes, they are prone to kidney problems, perhaps because the kidneys did not develop properly during the diabetic pregnancy. In the same families with the same genetic risk for diabetes, Pima children born before the mother developed diabetes did not develop diabetes at the same early age as the children born after the mother developed diabetes.³⁹ Thus, diabetes in pregnancy means far more to an Indian family than increased chances of a heavy baby and obstetrical complications at the time of the delivery.

Healthy lifestyles for the whole family offer the best chance to avoid the devastating consequences of diabetes in pregnancy. Many tribes are using their grants to begin to address these concerns.

Today doctors and families are recognizing a growing number of children with type 2 diabetes on Indian reservations -- a condition that until recently was simply considered impossible.³⁷ All children were thought to have type 1 or insulin deficient diabetes. Children with type 1 diabetes are dependent on insulin injections for life. Many Indian children with diabetes are overweight, and their mothers were diabetic during the pregnancy. There is now a growing recognition in all

communities that children can have type 2 diabetes and that studies are needed to determine the best forms of therapy for these young people. This is another example where the experience of Indian communities and the knowledge gained from the research studies is changing how diabetes is diagnosed and treated across the world.

Diabetes Across Generations

The studies that show the effects of diabetes in pregnancy across generations have only recently been extended to the non-Indian community, but the effects of diabetes in pregnancy across generations are a concern in all communities.³⁸ In Alaska where rates of diabetes have been quite low compared to rates in the continental U.S., gestational diabetes was not uncommon. But gestational diabetes only became apparent when the proper screening programs were instituted. It may be that diabetes in the young pregnant women is often unrecognized unless the proper screening takes place. Investigators have termed this a “vicious cycle.”³⁸ As diabetes is increasing across the developing world, many other communities are experiencing the effects of diabetes across generations.

With my first child I didn't have the gestational diabetes, but with my second I found out probably in my third or fourth month that I had it.

When I learned I had it, I told my boyfriend . . . I told him that I had to take insulin, he didn't want me to take insulin because of thinking it was going to harm the baby. I told a couple of family members, and they were against me taking the insulin too. I was pretty much confused about that part.

I got support from the diabetic people here in the hospital--the educators and dietitian. And I did a lot of reading on it . . . I had my boyfriend talk to the nurse and he finally understood what I had to do, for the baby's sake . . . It was a big reward at the end.

Roxanne Jojola, Isleta Pueblo

Prevention Efforts for Young Women

Tribes must use the information and experience to develop the types of medical care and community prevention needed. However, this is not an easy task. Young women of childbearing years have many family responsibilities and “leisure” time is scarce. Frequent checkups for mother

and baby are a burden. Yet these young women have a big challenge. The family lifestyle can affect their chances of getting diabetes and the chances of their children getting diabetes, especially children born of a diabetic pregnancy.

Preventing diabetes in Indian communities starts with preventing diabetes in pregnancy. Many years of medical research has shown how diabetic mothers can deliver healthy babies. In 1999 screening and special prenatal care have changed the prognosis for the diabetic pregnancy. Tribes must now find the best ways to prevent diabetes from developing subsequently both in these young women and in their offspring.

Future Directions

National Diabetes Prevention Center (NDPC)

The 1998 Department of Labor, Health and Human Services, Education, and Related Agencies Appropriations Act authorized the Centers for Disease Control and Prevention (CDC) to establish a *National Diabetes Prevention Center (NDPC)* in Gallup, New Mexico. The sum of \$2 million was appropriated for the Center.

In addition, as recommended by the tribal leaders in their consultation process for the *Special Diabetes Program* for Indians, \$1 million was set aside each year of the 5-year program for the Center. The intent of the tribal leaders in contributing these funds was to ensure that the Center would eventually serve all tribes and would support primary, secondary, and tertiary diabetes prevention research. In 1998, a cooperative agreement between IHS and CDC led to an award of \$2.3 million to the University of New Mexico Prevention Research Center to establish a National Diabetes Prevention Center in Gallup, New Mexico.

The *National Diabetes Prevention Center* is guided by several advisory bodies. The steering committee recommends future directions and activities at the Center. The steering committee includes members of NDPC staff and representatives of the founding partners including the Navajo Nation, Pueblo of Zuni, Zuni-Ramah IHS Service Unit, Gallup Indian Medical Center, Dine College, and representatives from CDC and IHS. The Tribal Leaders Diabetes Committee also serves as an advisory body to the Center.

The Center Advisory Board is composed of 15 members who represent a variety of national and regional interests related to Indian health. The Center Advisory Board's role is to provide advice and recommendations on the NDPC's overall direction, program activities, and expansion.

The purpose of the Center is to provide guidance and technical assistance regarding diabetes prevention in AI/AN communities. Initial activities target diabetes in the Navajo Nation and Zuni Pueblo as directed by the legislation. The Center's research efforts are in four major areas:

- ! Information and resources
- ! Research and evaluation
- ! Networking and collaboration
- ! Education and training

The *National Diabetes Prevention Center's* key accomplishments to date include:

- ! Formation of an expert panel
- ! Development of a formative evaluation process for the Center
- ! Collaborations with Dine College and other tribal colleges
- ! Information sharing at national conferences
- ! Sponsorship of a southwest regional conference that showcased local diabetes activities and projects, offered technical assistance workshops to the general audience, and provided expert panel technical assistance to answer specific research questions.
- ! Solicitation of prevention research projects from the Pueblo of Zuni, Zuni-Ramah IHS Service Unit, Navajo Nation, Dine College, and Gallup Indian Medical Center.

Regional Meetings

Expansion of the *National Diabetes Prevention Center*, so that it can address diabetes prevention research questions at the national level, is very important to tribal groups across the U.S. Eight regional meetings with tribal diabetes grant programs are planned in the Year 2000. The hope is that the meetings will provide information and guidance on how best to expand the Center's research activities. The regional meetings are scheduled for Anchorage, Spokane, Sacramento, Minneapolis, Phoenix, Nashville, Tulsa, and Albuquerque. These meetings will also provide an opportunity to:

- ! Showcase grant programs
- ! Share concerns and offer help
- ! Promote regional networks
- ! Provide updates on the grants process
- ! Describe the national scene for data, surveillance, and advocacy for continuing grant funds

Diabetes Education Reimbursement

The Health Care Financing Administration (HCFA) published the proposed rules for Expanded Coverage for Outpatient Diabetes Self- Management Training Services for Medicare in February 1999. The IHS National Diabetes Program submitted comments on the proposed HCFA rules as it would affect education services within Indian communities. Concerns included eligibility criteria, access issues, educational service limitations, and credentialing of diabetes education providers.

The IHS National Diabetes Program, with agency and tribal leader support, is taking the lead in establishing an Indian Health Diabetes Education Accreditation Program. This will allow the development of a flexible process to certify Indian health diabetes education programs and allow AI/AN education programs to seek medicare reimbursement.

The IHS has a process in place for diabetes program review.³⁹ This process integrates medical and educational standards that parallel the American Diabetes Association (ADA) Clinical Practice Recommendation and the National Standards for Diabetes Education. The IHS Integrated Standards includes review criteria to measure the quality of diabetes care and education in AI/AN communities. The IHS National Diabetes Program introduced the diabetes review process in 1987 after several Indian health programs reported the ADA Diabetes Education Recognition Program was too costly and contained review criteria that did not reflect the needs of Indian communities.

In April 1999, the IHS National Diabetes Program formed a workgroup to begin developing the framework to become an HCFA Diabetes Education Program Certification Entity. This workgroup consists of representatives from the Tribal Leader Diabetes Committee, National Indian Health Board, Urban Indian Programs, Model Diabetes Programs and the Area Diabetes Consultant Network. This workgroup also includes professionals with demonstrated skill and experience in diabetes education within Indian communities.



If I were a new diabetic, I would really get all I could on diabetes and learn, 'cause at that time I didn't know nothing about it and there was no information free like it is now. There's loads of information about being a diabetic and how to take care of yourself.

But . . . 24 years ago . . . there was hardly none. No information. But now there is and you can pick up a booklet and it tells you how to take care of yourself, how not to go barefooted and all of these things are in there and that's very important message in those pamphlets.

So . . . I would dig up all the information I could about diabetes and inform your family so if you have to cook a certain way, your family will join you.

Betty Thin Elk, Rosebud (Sioux), has had diabetes for 24 years

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